SUPPORTING EQUITABLE PARTNERSHIPS IN GLOBAL HEALTH

A TOOLKIT FOR PARTICIPATORY HEALTH RESEARCH METHODS

ABBREVIATIONS

ALHIV	Adolescents living with HIV
ARISE	Accountability and Responsiveness in Informal Settlements for Equity
CBPR	Community-based participatory research
CDDs	Community Directed Distributors
CESHHAR	The Centre for Sexual Health and HIV/AIDS Research Zimbabwe
CHV	Community health volunteer
DIPH	Department of International Health
FCDO	Foreign, Commonwealth and Development Office
FGD	Focus group discussion
FGS	Female genital schistosomiasis
FSW	Female sex worker
GIS	Geographic Information System
HIV	Human Immunodeficiency Virus
IEC	Information, education and communication
LSTM	Liverpool School of Tropical Medicine
LGA	Local government area
MAM	Mass Administration of Medicine
MDD	Major depressive disorder
MLW	Malawi-Liverpool-Wellcome Trust Clinical Research Programme
MRC DTP	Medical Research Committee Doctoral Training Programme
NGO	Non-governmental organisation
PAR	Participatory Action Research
PDSA	Plan, do, study, act
PHR	Participatory Health Research
PGP	Participatory Guide to Planning equitable MAM
PLA	Participatory Learning and Action
PTA	Problem tree analysis
PRA	Participatory Rural Appraisal
PW	Participatory Workshops
QI	Quality Improvement
RRA	Rapid Rural Appraisal
SSSDs	Severe stigmatising skin diseases
TB	Tuberculosis
UL PIRE	University of Liberia-Pacific Institute for Research and Evaluation
UK	United Kingdom

PURPOSE OF THE TOOLKIT

This toolkit will be useful to researchers, programme implementers, teachers and students who are interested in applying Participatory Health Research (PHR) methods to support equitable partnerships in global health.

AIM AND OBJECTIVES:

To provide a toolkit of PHR paradigms, methodologies and methods that can be selected and applied by researchers aiming to maximise inclusion, participation, and the achievement of more equitable research partnerships.

✅ To share examples of PHR approaches and methods that have been applied by researchers across the Department of International Public Health (DIPH) at the Liverpool School of Tropical Medicine (LSTM), with the aim of promoting equitable partnerships in global health.

✅ To identify challenges and benefits of different PHR approaches and methods.

✅ To raise the profile of PHR and make its methods accessible to people who are new to PHR.

LEARNING OUTCOMES:

Through engaging with this toolkit, you will be able to:

- Define what PHR is.
- Identify and select different PHR methodologies and methods that are relevant for your project.
- Apply and critique the methods in current and future PHR projects.
- Understand the benefits and challenges of using PHR methods, with specific focus on strengthening participation, collaboration, and equitable health outcomes.
- Consider the values and principles of PHR to maximise quality, rigour, and trustworthiness.

This toolkit is presented in two modules. The first module introduces core concepts and approaches in PHR, as well as an introduction to research within the DIPH at LSTM. The second module explores different methods which can be used in PHR for data collection and sharing of research findings, and is divided into three thematic areas:

1. Understanding community structures across time and space;

2. Understanding community perspectives and lived realities; and

3. Mapping stakeholders and processes.

MODULE ONE

INTRODUCTION TO PARTICIPATORY HEALTH RESEARCH

1. INTRODUCTION TO PARTICIPATORY HEALTH RESEARCH

THE AIM OF THIS SECTION IS TO:

✓ Introduce core concepts and values of PHR in the context of global health.

✓ Reflect on terminology and its role in decolonising approaches to global health.

✓ Introduce the partners and organisations at LSTM's DIPH and the background of their research.

BACKGROUND TO PHR AND DECOLONISING APPROACHES IN GLOBAL HEALTH

WHAT IS GLOBAL HEALTH?

Establishing an understanding of 'global health' is essential when embarking on participatory health research. While interest in defining 'global health' has increased over the last decade, it remains a contested concept and definitions are unclear. In a recent review exploring the concept and definition of global health, Salm et al (2021) argue that a shift is needed to question not 'what is global health?' but rather 'who' defines global health and for what purpose. Global health is an emerging concept and broadly defined as **'an area of research and practice committed to the application of overtly multidisciplinary, multisectoral and culturally sensitive approaches for reducing health disparities that transcend national borders'** (Salm et al., 2021, page 11).

Salm 2021 identified four themes within the systematic review which explores global health as:

1 A domain of research, healthcare and education, which is multifaceted, across disciplines, sectors, cultures and nations.

2 Rooted in values of equity and social justice.

3 A mode of governance that yields influence through political decision-making, problem identification, and the allocation and exchange of resources across borders.

4 An emerging concept with multiple meanings and vague definitions. Although linked, global health's similarities and distinctions from tropical medicine, international health, and public health are contested. (Salm et al., 2021, page 12).

Rooted in values of equity and social justice, the broad definition of global health refers to reducing health disparities through research, healthcare and education across multifaceted sectors across borders, cultures and disciplines; this requires equitable partnerships. However, global health research can perpetuate existing power imbalances, as knowledge production is still too often dominated by academics and stakeholders at higher levels of the health system. PHR aims to recognise and address these inequities as a collaborative approach, whereby multiple stakeholders, including local communities, play an active role in research on issues that are fundamental to their lives.

BACKGROUND TO PHR

Originating in the 'Global South' also termed **majority world*** in the 1970s, PHR focuses on partnership and the **co-production of knowledge** through prioritising local forms of knowledge (Chambers, 1981, Freire, 1970). The research process is not done "on" people but "with" them, to shape understandings grounded in the lived realities of communities so that they can act on issues that directly affect them. PHR has a focus on equity and aims to prioritise the needs of marginalised and socially excluded groups.

> *"The goal of PHR is to maximise the participation of those whose life or work is the subject of the research in all stages of the research process…Research is not done "on" people as passive subjects providing "data" but "with" them to provide relevant information for improving their lives."*
>
> *(International Collaboration for Participatory Health Research, 2013)*

Participation is central to PHR as a research paradigm, which enables researchers, **communities** and **stakeholders** to work together in a co-learning process to provide action for change. However, all PHR must address issues of power and challenges of co-learning which will be explored in this toolkit.

Defining a **community** in PHR can be ambiguous, as communities differ according to settings and experiences. MacQueen et al., (2001) define community as: "a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings". Community can also refer to "a specific group of people, usually living in a defined geographical area, who may share common values, norms, culture and customs, and are arranged in a social structure according to relationships which the community has collectively developed over a period of time." (Ministry of Health, 2014).

Within this toolkit, communities are conceptualised as a wider group of people which incorporates stakeholders from throughout the health system within the countries where the research is being implemented. **Co-researchers** are conceptualised as lay researchers from communities, as well as local or national health systems actors (health providers, decision-makers) or stakeholders. Co-researchers work with researchers in developing and directing research ideas, collecting and analysing data, and disseminating findings. Co-researchers are fundamental for co-learning in PHR, and for supporting active learning and transformational change in the community.

*Majority world *– in this toolkit, we refer to 'majority world' as an alternative to 'Global South', 'developing' or 'low-income' as these terms can have negative connotations. As argued by Sham (2008), these terms often "reinforce stereotypes about poor communities…, while hiding their histories of oppression and exploitation…These labels also hinder the appreciation of the cultural and social wealth of these communities" (Sham, 2008, page 88). Majority world is geographically accurate and an alternative to these hierarchical terms.*

WHAT IS DECOLONISING GLOBAL HEALTH AND WHY IS IT IMPORTANT IN PHR?

Decolonising global health is about recognising that its history is rooted in colonial and tropical medicine, underlined by western Eurocentric understandings of health and the human body as the norm. Furthermore, it acknowledges that research processes have often been extractive, while producing processes of othering (Affun-Adegbulu and Adegbulu, 2020). These power imbalances continue to inform global health systems by perpetuating top-down practices and policies that often position the 'West', and institutions in high-income countries, former colonisers, as the 'experts' in knowledge, science and research, telling 'poor people' in 'former' colonies, how to improve their health (Khan et al., 2021). Decolonising global health is therefore not only about acknowledging its colonial legacy but countering it. PHR can be used as a tool to counter this colonial legacy, through redressing these power imbalances as:

1. It is a non-Western methodology that hails from a majority world context where it was used to drive social change.

2. It is owned by communities, not researchers and de-centres the role of the researcher and their "expert" knowledge, shifting the understanding of expertise to community members.

3. It often relies upon and honours indigenous knowledge systems, many of which were intentionally repressed, if not made illegal, under colonial regimes. This has an aftermath of demeaning indigenous knowledge systems as quackery, when, in many cases, this is generational knowledge, which has been tried and tested across hundreds of years.

Therefore, when PHR methods and methodologies are carried out in majority world settings, PHR can confront many of the ingrained hierarchies that stem from colonisation and can reverse them. However, it is important to recognise that PHR alone is not a panacea to decolonising global health, but as a contributing tool, in a growing repertoire of approaches and actions that are necessary to truly facilitate and embed the many shifts that are called for in movements to decolonise global health. Furthermore, the mindset and approach of people using PHR must be one of active decolonisation to avoid perpetuating the engrained power hierarchies within global health research. Participatory methods can help to address and counter imbalances in power, by promoting the inclusion and ownership of community as partners in research. This toolkit focuses on participatory approaches and methods used in PHR that are inclusive of stakeholders and communities as experts of their own realities.

CONTRIBUTING CONSORTIUMS & PARTNER ORGANISATIONS

This tool has been co-produced with researchers across the DIPH at LSTM and international research partners involved in research consortiums which aim to address inequities in global health in a variety of ways. Methods, methodologies and case studies included in this toolkit span different research disciplines, health priorities, contents, and inequities. The strength of this toolkit is the illustration of PHR methods through case studies from our collaborative research. Case studies demonstrate the application of methods to real-life global health and health systems problems, with a specific focus on health equity. We discuss the challenges and benefits that we encountered when using the different methods and approaches.

Below is a brief introduction to the consortiums which have contributed to the case studies and toolkit.

COUNTDOWN

COUNTDOWN is a 7-year programme of Neglected Tropical Disease (NTD) implementation research funded by UKAID within the UK Foreign, Commonwealth and Development Office (FCDO). COUNTDOWN brings together researchers from a range of backgrounds, policy makers, health care providers and implementation research specialists from Cameroon, Ghana, Liberia, Nigeria, the UK and the USA.

"Our strategy is to increase the effectiveness of NTD programmes, with a focus on reaching poor and vulnerable groups and highlighting inequities, resulting in more people accessing appropriate interventions and receiving necessary treatments."

COUNTDOWN uses participatory research approaches to address health system challenges for neglected tropical diseases. We present a range of case studies developed by researchers who work with the Ministries of Health within all countries as well as; Sightsavers Nigeria, University of Liberia, Pacific Institute for Research and Evaluation; FHI360 (USA); University of Buea (Cameroon); Centre for Schistosomiasis and Parasitology (Cameroon); Dodowa Health Research Centre (Ghana); The Council for Scientific and Industrial Research, Water Research Institute (Ghana); and the LSTM (UK).

Visit: **countdown.lstmed.ac.uk**

ARISE

The ARISE Hub - Accountability and Responsiveness in Informal Settlements for Equity - is funded by UKRI's Global Challenges Research Fund. ARISE was set up to enhance accountability and improve the health and wellbeing of marginalised populations living in informal urban settlements in LMICs. ARISE uses Community-Based Participatory Research (CBPR) and partners include: African Population and Health Research Centre (Kenya), College of Medicine and Allied Health Sciences (Sierra Leone), George Institute for Global Health (India), Institute of Development Studies (UK), Institute of Health and Wellbeing at The University of Glasgow (UK), James P Grant School of Public Health BRAC University (Bangladesh), LSTM (UK), LVCT Health (Kenya), Slum/Shack Dwellers International (India), and the University of York (UK).

"ARISE will collect data, build capacity and support people to exercise their right to health. We will work closely with - and be guided by - communities themselves: vulnerable people living in informal settlements who are often 'off the map'."

Visit: **www.lstmed.ac.uk/research/collaborations/arise-hub**

REBUILD FOR RESILIENCE

ReBUILD for Resilience examines health system resilience in fragile settings experiencing violence, conflict, pandemics, and other shocks. Partners are based in Lebanon, Myanmar, Nepal, Sierra Leone and the UK and include the American University of Beirut (Lebanon), Burnet Institute (Myanmar), College of Medicine and Allied Health Sciences (Sierra Leone), Herd International (Nepal), Queen Margaret University (UK) and LSTM (UK).

Visit: www.rebuildconsortium.com/partners

REDRESS

REDRESS aims to reduce illness, stigma, social exclusion, and poverty caused by severe stigmatising skin diseases (SSSDs) in Liberia. Several Neglected Tropical Diseases (NTDs) manifests in the skin, including destructive skin ulcers and elephantiasis. REDRESS centres PHR to support the strengthening of person-centred integrated management approaches for SSSDs. REDRESS is funded by National Institute of Health Research, and works collaboratively with Liberia Ministry of Health, University of Liberia Pacific Institute for Research and Evaluation, Actions Transforming Lives, American Leprosy Mission, Effect: Hope, and Queen Margaret University.

Visit: www.redressliberia.org

THE CENTRE FOR SEXUAL HEALTH AND HIV / AIDS RESEARCH (CESHHAR) ZIMBABWE

CeSHHAR Zimbabwe was initially established in 1999 (then known as the Regai Dzive Shiri Project), and became a trust in 2012. CeSHHAR's mission is *"to conduct research, deliver programmes, and strengthen capacity to inform health policy and programming in Zimbabwe and beyond."* Values are centred around producing locally appropriate and culturally relevant public health research, in consultation with communities and stakeholders.

Visit: ceshhar.org

MALAWI-LIVERPOOL-WELLCOME TRUST CLINICAL RESEARCH PROGRAMME (MLW)

The Malawi-Liverpool Wellcome Trust Clinical Research Programme's mission is to conduct high quality research to improve health and to train the next generation of researchers. Research is focused on six main themes including: population health, social sciences, Maternal, Neonatal and Child Health, vaccines, clinical and experimental medicine, and infection biology.

Visit: www.mlw.mw/about

KEY FRAMEWORKS OF PHR

PHR is a collective description of several **research paradigms or approaches** that use cycles of reflection and action. These paradigms are all based on shared values of; (1) Participation and collaboration; (2) Continuous reflection and action cycles (for example, planning, acting, observing and reflecting); (3) Generation of knowledge; and (4) Transformation of practice (Cordeiro et al., 2017). The terms below capture paradigms and approaches that are used across DIPH research partnerships:

- **Action research**
- **Participatory research**
- **Rapid Rural Appraisal (RRA)**
- **Participatory rural appraisal (PRA)**
- **Participatory learning and action (PLA)**
- **Participative inquiry and practice**

These approaches are different to **participatory research methods,** which can be utilised at different stages of a PHR action cycle to co-produce new knowledge that may or may not be used for collective action. PAR, CBPR and Quality Improvement (QI) approaches are all part of the PHR paradigm. However, they have slightly different methodological principles, which are described below.

PARTICIPATORY ACTION RESEARCH

PAR has been described as an umbrella term for participatory action-orientated research (Kindon et al., 2007). The aim of PAR is to enable action for positive change through reflection and collective knowledge (Baum et al., 2006). Cycles of reflection and action are embedded within the research process to promote sustainable and transformational change, drawing on a bottom-up approach to identifying problems and co-producing solutions which are context specific. PAR enables researchers and co-researchers from communities and other stakeholder groups to work together to co-produce knowledge and actions, and to evaluate and reflect on those actions within an iterative cyclical process (fig 1).

PARTICIPATORY EXPLORATORY RESEARCH: PHASE ONE
Co-production of solutions to implementation challenges with co-researchers

PLAN: PHASE TWO
Development of action plans and implementation strategies with co-researchers

REFLECT: PHASE FOUR
Reflections on implementation of action plans with co-researchers

STEPS TOWARDS A PARTICIPATORY ACTION RESEARCH CYCLE

ACT: PHASE THREE
Implementation of action plans in selected areas

OBSERVE: PHASE THREE
Use of evaluation tools / methods to observe the implementation process

Figure 1: Participatory Action Research Cycle

COMMUNITY-BASED PARTICIPATORY RESEARCH

CBPR is a collaborative approach in which the community participates in all aspects of the research process. It aims to promote equity, combining community knowledge with action to effect change, helping to improve health and well-being in the communities involved (Isreal, 1998, Minkler, 2003). CBPR seeks to identify and build on existing community strengths and resources , supporting partnerships between academics and communities to produce outcomes that are relevant and useful to the community.

Equitable partnerships in CBPR require sharing knowledge, power and resources at each stage of the research process. This includes defining the problem, choosing the research design, collecting and analysing data, and determining how the results should be used for action. CBPR is an iterative, cyclical process, which incorporates research, reflection, and action. You can read about how CBPR was used in a case study to establish support groups on page 49.
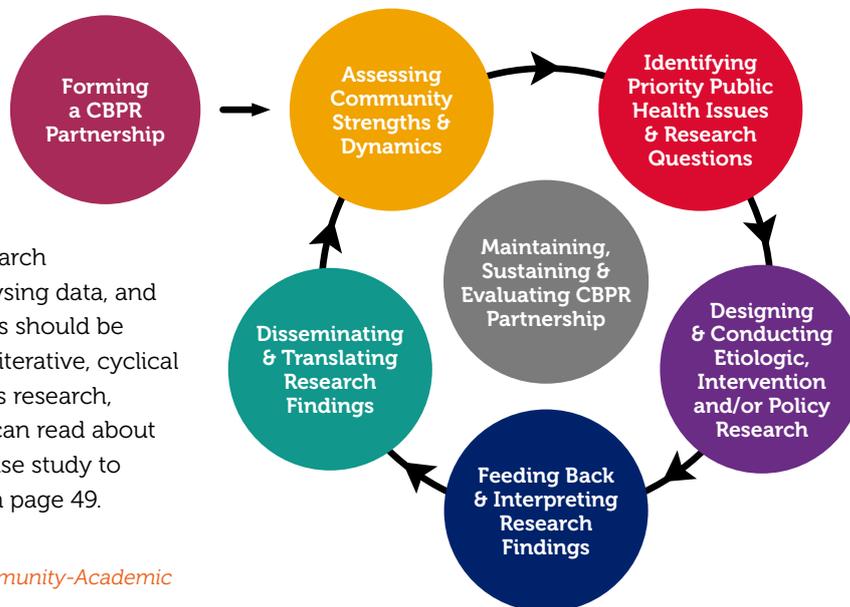
Figure 2: Source: Detroit Community-Academic Urban Research Centre, 2011

Circle diagram labels: Forming a CBPR Partnership → Assessing Community Strengths & Dynamics → Identifying Priority Public Health Issues & Research Questions → Designing & Conducting Etiologic, Intervention and/or Policy Research → Feeding Back & Interpreting Research Findings → Disseminating & Translating Research Findings → (back to Assessing Community Strengths & Dynamics). Centre: Maintaining, Sustaining & Evaluating CBPR Partnership

QUALITY IMPROVEMENT

The QI approach is a participatory research approach that implements a cycle of planning and action for change, allowing for uptake of research findings while simultaneously embedding change within health systems for sustainability (Martineau et al., 2018, Tetui et al., 2017). QI, also known as the Plan-Do-Study-Act (PDSA) cycle, provides a structure of iterative testing of change across a four-stage learning process aimed at improving quality of systems (Taylor MJ et al., 2014). In the 'plan' stage, a change aimed at improvement is identified and detailed, tasks assigned, and expectations confirmed. At the 'do' stage the plan is implemented, and any deviation from the plan is documented. At the 'study' stage the results from the test cycle are studied, and questions are asked regarding what went right or wrong and should be changed in the next test cycle. Finally, the 'act' stage examines the lessons learned from the study phase and identifies adaptations and next steps to inform a new cycle or to implement the change (Varkey et al., 2007).

PLAN: Identify change aimed at improvement. Assign tasks and expected outcomes

DO: Implement the plan and document any deviations from the plan

STUDY: Study the implementation, identify what went well and what did not

ACT: Examine lessons from the study stage. Identify adaptations and next steps

Figure 3: Quality Improvement Cycle

The PDSA cycle provides a platform of testing interventions using a small-scale iterative approach which enables rapid assessments and builds evidence for fit-for-purpose solutions within the context, while engaging actors within the context for sustainable change (Taylor MJ et al., 2014).

CASE STUDY

A QI APPROACH FOR FEMALE GENITAL SCHISTOSOMIASIS RESEARCH IN LIBERIA
(BY MOTTO NGANDA ON BEHALF OF COUNTDOWN)

This primary health care intervention study aimed to integrate the diagnosis, treatment, and management of female genital schistosomiasis (FGS) into the primary healthcare system in Liberia. The study drew on the QI approach using the PDSA cycle to develop and pilot a package of care for women with symptoms of FGS in schistosomiasis endemic areas in Liberia. The PDSA cycle used in this study is outlined below:

1. PLAN: Activities to be implemented within the QI cycles were generated using Participatory Workshops (PWs) called learning sessions, researchers and stakeholders collaboratively developed diagnosis and treatment algorithms for FGS including referral and support systems. They developed a plan of action for implementation and uptake and established a QI team (a small group of participants of the workshops) to support implementation and uptake.

2. DO: Action plans developed during the 'Plan' stage were implemented. This included capacity building of health workers on FGS and implementation of the diagnostic, treatment, and management algorithms in their respective health facilities. They also took note of any deviations to the algorithms when diagnosing and treating women and girls.

3. STUDY: Implementation of the plans in the 'Do' stage was monitored, to test their acceptability and effectiveness within the setting. Activities in this stage included site visits to implementation health facilities by the QI team supported by the core study team, interviews with women diagnosed and health workers, and analysis of FGS cases registers.

4. ACT: Learnings from the 'Study' stage were integrated and used to adapt the diagnostic, treatment, and management algorithms are embedded within plans for the next cycle of testing the intervention, or to complete the process. Plans for scale-up of successful intervention components within routine health system activities were also developed.

The figure below summarises the QI approach used for the FGS study in Liberia (adapted from, Wagner et al., 2001).
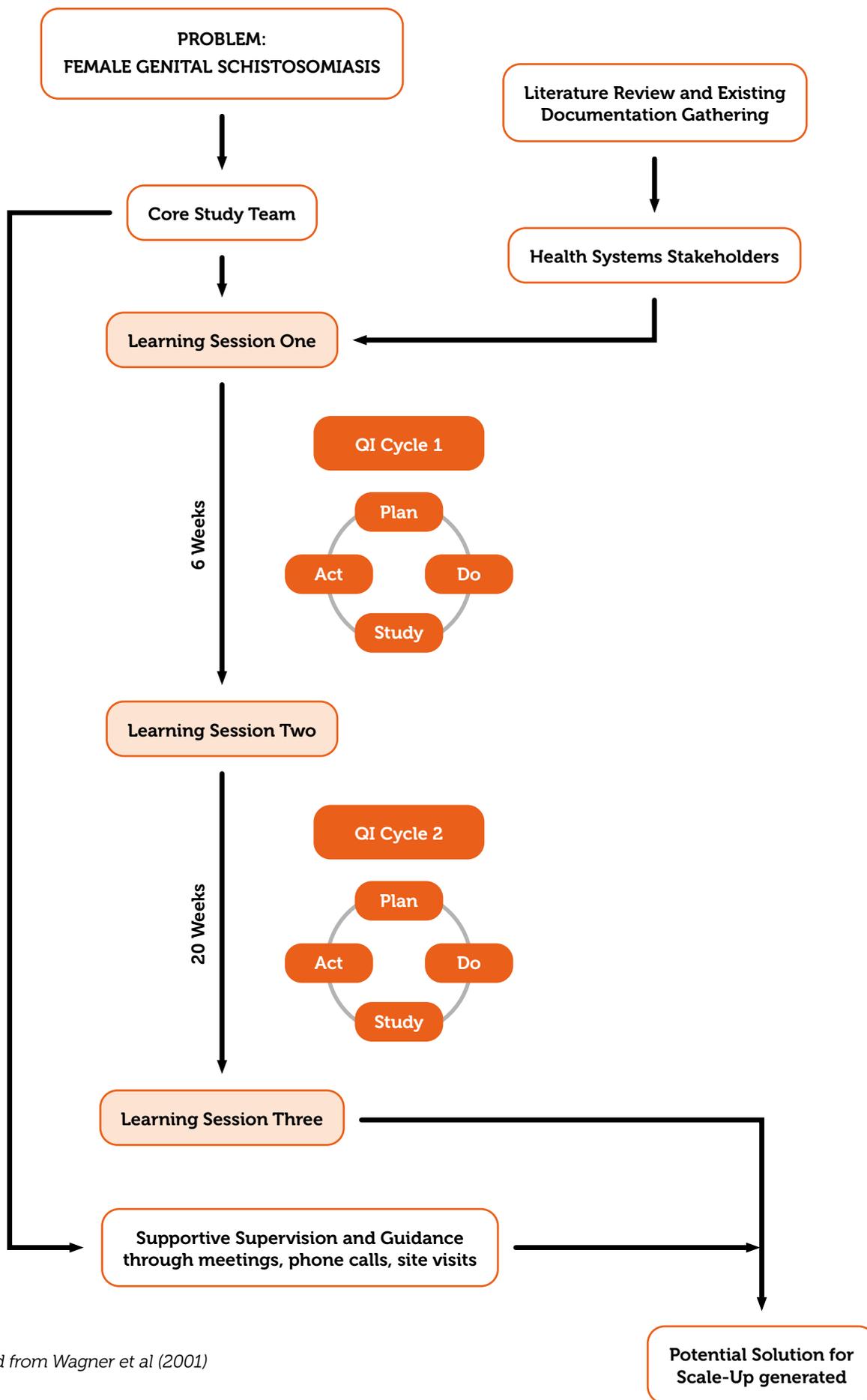
Adapted from Wagner et al (2001)

Figure 4: *Flow diagram on the quality improvement study on FGS*

CASE STUDY

USING PAR TO IMPROVE EQUITY IN NEGLECTED TROPICAL DISEASE PROGRAMMES IN NIGERIA

(BY HELEN PIOTROWSKI AND KIM OZANO ON BEHALF OF COUNTDOWN)

COUNTDOWN
Calling time on Neglected Tropical Diseases

A situational analysis with communities and health system actors in Nigeria identified that coverage of mass administrations of medicines (MAM) to prevent and treat NTDs in endemic communities was limited. This was due to a top-down approach which did not consider changing contexts including factors such as migration and urbanisation. There was disengagement with communities and a lack of community ownership of the programme due to programme fatigue and funding limitations. Furthermore, specific populations such as people with disabilities, women, migrant communities and farmers were often missed from sensitisation, mobilisation and medicine distribution.

Solutions to address these challenges and maximise equitable coverage of medicines were co-developed with communities and health system actors from the Nigerian health system, in the Local Government Area (LGA) and the state. Actions were then implemented and evaluated during subsequent MAM and reflected upon (Fig 5). The participatory approach to planning and implementing MAM was piloted in NTD programmes in two Nigerian states (Ogun and Kaduna) and resulted in increased community ownership and engagement, mobilisation of resources from stakeholders to maximise the reach of the programme, and increased acceptance and coverage. The approach also empowered and motivated implementers at state and local level, including Community Drug Distributors, through strengthening capacities to engage with communities in enhanced training and supervision. COUNTDOWN generated lessons for policy and practice that could transform other health programmes.

PARTICIPATORY EXPLORATORY RESEARCH: PHASE ONE
Co-production of solutions to implementation challenges with communities, frontline health workers, NTD implementers and other stakeholders

Review and revise action plans for re-implementation

PLAN: PHASE TWO
Development of action plans and implementation strategies with health systems actors to address implementation challenges using new knowledge produced by communities

REFLECT: PHASE FOUR
Reflections on implementation of action plans and the impact on programmatic challenges with health systems actors and communities

STEPS TOWARDS A PARTICIPATORY ACTION RESEARCH CYCLE

ACT: PHASE THREE
Implementation of action plans in selected areas

OBSERVE: PHASE THREE
Use of evaluation tools to observe the implementation process; ethnography, actions logs, photo elicitation, problem tree analysis, coverage surveys etc

Figure 5: PAR to address equity in NTD programmes (COUNTDOWN consortium, 2019, adapted from Kindon et al,. 2007).

ETHICAL PRINCIPLES OF PAR

Within health systems, PAR can challenge top-down approaches to policy and practice, which can address structural barriers which perpetuate inequalities. Many of the case studies presented in module 2 have used a PAR approach to strengthening health programmes. Figure 6 shows the iterative process of PAR and how it can be applied to health systems to promote ethical and equitable change.

Promotes joint problem and solution finding between communities and health systems actors through the use of creative participatory methods for meaningful participation and ownership

Potential outcomes for health systems and implementation challenges

Embeds evidence-informed health policy development with mechanisms that equip policy makers and implementers with the tools to support change, including accessible evidence produced from the research partners

Supports policy and service implementation analysis at all levels of the health system and opportunities to expand and grow ideas that do not disrupt health systems but allow time to embed new ideas and concepts

Principle 1
Recognise communities as units of identity and define stakeholder participation to ensure equitable engagement of all actors

Principle 5
Develop structures for ongoing learning at multiple levels of the health system

Five principles for high quality, ethical PAR to address implementation challenges for health systems strengthening

Principle 2
Enable flexible action planning that builds on existing structures whilst providing opportunities for embedding change

Principle 4
Embed relational practices that lead to new political forms of participation and inquiry within health systems

Principle 3
Address health systems and research power differentials that can impede co-production of knowledge and solution development

Improves quality of relations during the inquiry that challenge existing political forms and enable the potential for ongoing and sustainable forms of participation within health systems design and delivery

Application of quality standards and principles for Participatory Action Research through active reflexivity at every stage in the research process

Challenges top-down approaches, addresses structural barriers to participation and present opportunities for local level actors to add innovation and creativity to localised problems

Figure 6: Ethical principles for PAR in health system strengthening (Ozano et al., 2020)

PHR PRINCIPLE AND CORE VALUES

Listed below are ten principles which underpin the CBPR paradigm, as identified by Israel et al. (2017):

- Recognises communities as a unit of identity
- Integrates and achieves a balance between research and action for the mutual benefit of all partners
- Involves systems development through a cyclical and iterative process
- Builds on strengths and resources in the community
- Facilitates collaborative, equitable partnerships in all research phases and involves an empowering and power-sharing process that attends to social inequalities
- Promotes co-learning and capacity building among all partners
- Disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process
- Emphasises public health problems of local relevance and ecological perspectives that attend to the multiple determinants of health and disease
- Requires a long-term process and commitment to sustainability
- Addresses issues of race, ethnicity, racism, and social class and embraces 'cultural humility'

In this section we highlight PHR principles and core values, presenting case studies of how these principles can be realised within projects.

CO-RESEARCHERS

As discussed in the introduction, identifying and working with stakeholders as co-researchers (or peer-researchers) is a core principle of PHR. Co-researchers can take on a range of roles in the research process. While some community members may participate throughout the process, others may choose to participate only in select activities (e.g. to be part of decision-making processes without taking part in data collection). Co-researchers may take on roles such as:

- Participants in data collection activities, including co-analysis of the focal issue during participatory exercises;
- Co-organisers of data collection activities, for example recruiting participants and conducting informed consent processes
- Collectors of data, as either sole facilitators of participatory exercises or as co-facilitators with researchers
- Decision-makers, determining research priorities and research design together with researchers
- Co-analysts, looking together at data from across exercises with researchers and jointly identifying key findings
- Facilitators of ongoing processes of development
- Co-authors of outputs from participatory research processes

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POSITIONALITY

Positionality is a key concept in qualitative research. Positionality relates to the status of an individual which affects interpersonal relationships and that has the potential to affect the research process (Lian, 2019). Ozano (2018) defines positionality as "The way in which people view themselves and are viewed by others: as an insider or outsider, someone with power or who feels powerless, or coming from a privileged or disadvantaged situation". The positionality of all involved in research, including research assistants, co-researchers and participants, as well as the relations of power between them, are important factors that determine the quality of the research process, data and results. Therefore, locating one's own positionality and that of others involved in the participatory study, in terms of factors such as gender, age, race, ethnicity and life experience, should be considered during project design (Hendrix-Jenkins, 2020).

REFLEXIVITY

Reflexivity is an intentional process where researchers continuously reflect on what they know and how they know. As PHR draws together different researchers with varied experience, recognising their positionality and how this impacts the research is essential throughout the research process. It requires critical self-awareness and insight into our own histories, assumptions and personal biases. To support this process in PHR, all researchers can keep reflective journals or purposefully use methods to reflect collectively. This can ensure that research is valid and increase trustworthiness of evidence generated.

POWER DYNAMICS

The success of PHR depends on the quality of collaboration between the different actors in the research: researchers, co-researchers, and community members (Khan et al., 2021) . The purpose of the research may also dictate the degree to which actors have influence on each other and on how this influence is handled by the collaborating parties (Andress et al., 2020). Power dynamics are relational and shape the way in which people who differ by background, gender, race, class or age interact with each other in a setting (Andress et al., 2020). PHR approaches are often upheld as a means to achieve health equity and inclusion of all (Pratt, 2020). However, where pre-existing power relations or 'conditions' are not adequately considered, principles and values of PHR research including establishment of equitable partnerships, sharing of power, and democratic production of knowledge, can quickly become reduced to tokenism. This is particularly true amongst social groupings or communities who are frequently marginalised from processes that support collective action and change, for example, people with disabilities, migrant populations, slum dwellers. Thus, it is critically important to consider how stakeholders can be supported to navigate power structures within PHR projects. By actively considering power, PHR has the potential to meaningfully include alternative perspectives and competing ideas within overarching development processes.

DISSEMINATION

Dissemination refers to sharing findings and knowledge with the broader community in meaningful ways. In PHR, all partners are involved in the process to produce, interpret, and disseminate findings to community members in a way that is inclusive of and beneficial to the community. The dissemination of findings can inform the development of interventions and change in policy and practice. Therefore, it is vital to disseminate findings beyond scientific research papers. PHR aims at engaging community members in the interpretation of findings and co-production of research messages for different audiences. Power dynamics and language barriers are key considerations within dissemination processes (Evans, 2016). PHR is not limited to the production of knowledge but committed to using knowledge to improve health and well-being.

CASE STUDY

METHODS FOR MANAGING EXPECTATIONS AND BUILDING TRUST IN AN INFORMAL SETTLEMENT IN KENYA

(BY BEATE RINGWALD ON BEHALF OF ARISE)

In PHR, introductions matter as a first step on a journey to build trust among researchers and co-researchers (Abma et al., 2019). Approaches used for introductions should provide people with an opportunity to get to know each other without being intrusive.

Within ARISE, "Korogocho ALIV[H]E" is a CBPR study that aims to explore opportunities for strengthening community health systems' capacity to address the intersection between intimate partner violence and HIV intersection in an informal settlement in Nairobi, Kenya.

- **METHOD 1: DRAWING A TIMELINE**[1]**:** At the beginning of the training for researchers and programme staff involved in the "Korogocho ALIV[H]E" study, we provided crayons and big sheets of paper and asked everyone to illustrate three events to explain how they came to join the study. Everyone introduced themself and described their journey.

Picture drawn for timeline activity

- **METHOD 2: CHOOSING A PHOTO:** When researchers and co-researchers met as a research team for the first time, we mounted photos on the wall (about twice as many photos as the number of people present). We asked everyone to walk around and choose one picture that they related to, or that described something about them. Co-researchers and researchers then explained to each other why they had selected their picture.

BENEFITS AND CHALLENGES

These methods allow people to decide how much they want to say about themselves. They make introductions interesting because people will have the opportunity to tell their own stories. In our experience, these methods gave people a chance to start bonding, and to get a sense that the process and atmosphere of project might be different from what they had assumed.

In the training, some found drawing a timeline challenging as they had not drawn or used crayons for years, so we assured them that the picture did not need to be perfect. Most people shared joyful and traumatic life events in their timelines, and we reminded everyone that the content was confidential.

For the research team, we needed to ensure that nobody felt pressured to provide information about themselves that would expose or endanger them. This was particularly important for people from marginalised groups, because of the power differences between and among researchers and community co-researchers. Therefore, we selected a method and question broad enough to give people control over what they wanted to share.

TOP TIPS

Consider a wide range of photos that people can relate to. For this study, it was useful to select photos from Kenya. We sourced photos marked as dedicated to the public domain online.

Visit: creativecommons.org

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[1] *Method adapted from a participatory research training by Dr Nicola Burns, Lecturer in Disability Studies, School of Social and Political Sciences, University of Glasgow.*

USING "HANDA'S SURPRISE" TO DISCUSS POSITIONALITY AND RISK OF BIAS IN AN INFORMAL SETTLEMENT IN KENYA

(BY BEATE RINGWALD ON BEHALF OF ARISE)

In PHR collective reflexivity is a key component in all stages of the research process (Abma et al., 2019). Collective reflexivity requires space to think critically within the research team.

Within ARISE, "Korogocho ALIV[H]E" is a CBPR study that aims to explore opportunities for strengthening community health systems' capacity to address intimate partner violence and HIV intersection in an informal settlement in Nairobi, Kenya.

METHOD: We created a space for the research team to critically reflect on their own status, social power and potential for bias, using the famous children's book 'Handa's surprise' (Brown, 1994). In brief, in a fictional village in south-west Kenya, Handa carries a basket of different fruits as a gift to her friend Akeyo. Along the way, various wild animals pick fruits from the basket, one after the other. At the end, Handa is surprised to find the basket filled with tangerines, Akeyo's favourite fruit. Together, we reflected on what the story could tell us about analysis of qualitative data. We discussed how our own identities shape how we see the world, determine how much privilege and power we have and influence what opportunities are available to us.

BENEFITS AND CHALLENGES

Although community co-researchers had not heard of the book before, they could easily relate to the story. With the exercise, we initiated critical reflection on our own positionalities, opened conversations about power within the research team, and set the scene for subsequent group reflections. As researchers, we gained new insights into the lived experiences of co-researchers in the team.

As researchers, we had prepared for the session by discussing our reflections about the story and what it could tell us about data analysis and risk of bias. Community co-researchers broadened the reflections on the meaning of the story to the entire research process, including engagements with the community. Co-researchers explained that they also saw the life of Handa being at risk during her journey, because where wild animals live, there also are also lions. In co-researchers' narratives the invisible lion was a metaphor for risk, including risks that living in an informal settlement entail. The reflections on risk made us as researchers aware of our own privilege, represented by the absence of an invisible lion in our daily lives, and limitations to understand the study context. We also learned that using picture books may trigger associations that may not be foreseen because of the limitation of own positionality.

TOP TIPS

If the book is not available, researchers can also use the video of the book.

Visit: youtu.be/ocnRQi89nK8

NOTES
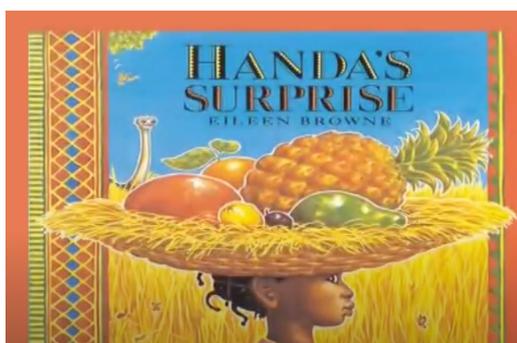
MODULE
TWO

PARTICIPATORY RESEARCH METHODS

2.1 UNDERSTANDING COMMUNITY STRUCTURES IN TIME AND SPACE

This section looks at a range of participatory methods, with a focus on understanding community structures. These methods can be used in different ways throughout PHR research cycles including to gather baseline data, or to plan for public health programmes, asking questions such as where is best to distribute medicines? When should programmes be implemented? Where are specific populations located? This section will:

- Introduce and provide step by step instructions on conducting participatory methods.
- Learn about case studies, which have used specific methods.
- Consider the strengths and challenges of these methods.
- Learn top tips for each method.

TRANSECT WALK

INTRODUCTION TO METHOD

This is a purposeful walk through a community with people from that community, such as community and religious leaders, youth groups or disabled persons organisations. The aim of the walk is to improve understanding of key structures and spaces in the community, and how community members interact within the community. For example, different structures and spaces may be utilised by different groups in the community, for example youths, men and women. During or following the walk, the information collected can then be presented as a map, diagram or chart.

The information collected on this walk can be used to strengthen public health programmes (see case study).

HOW TO DO METHOD

1. Identify key stakeholders or members within the community who could guide you on the walk.
2. Explain the purpose of the walk to the community member(s) and seek their consent.
3. If the community member(s) agree, you may wish to audio-record the discussion on your walk and later transcribe.
4. During the walk, take notes of places you observe, which community members are there, and how they are interacting.

5. Ask questions as you continue your walk to help stimulate discussion. Example questions may include:
- **What is located here?**
- **Who meets there?**
- **How frequently do people meet there?**
- **How long has this building/structure/landmark been there?**
- **Where do people collect water?**
- **Where do people collect firewood?**
- **Where do people pray?**
- **What times of day/year do people meet at specific places/complete specific activities?**
- **Where are the points and people of influence within the community located?**

6. Once you have completed your walk, take time to draw out the walk.
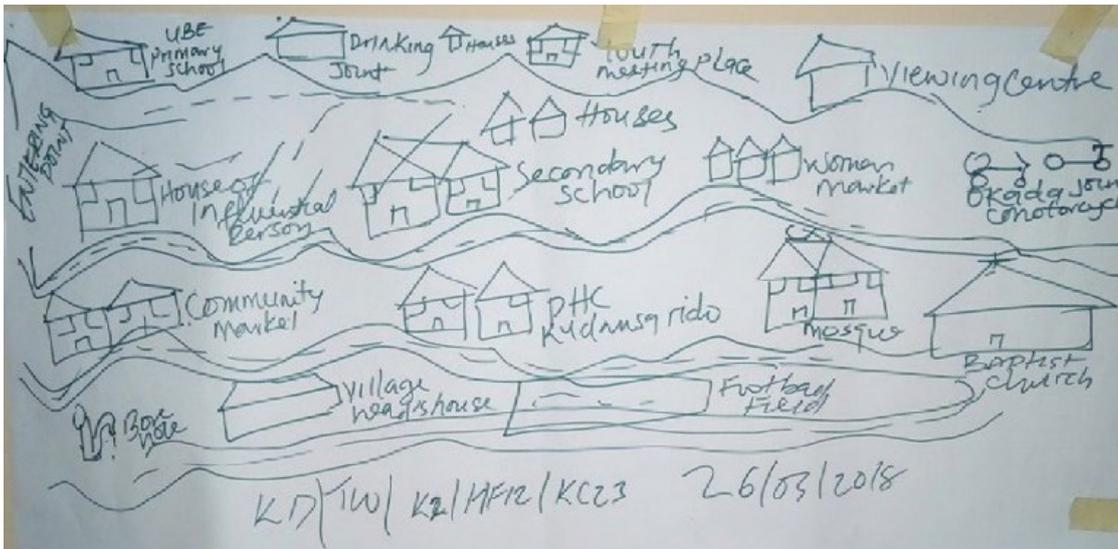
Community map

7. Draw a grid or table and reflect with community members on the features observed during the transect walk.

TYPE OF STRUCTURE (House, market etc.)			
WHO INTERACTS THERE (Men, women, children etc.)			
TIMES OF DAY			
TIMES OF YEAR			
CURRENT USE FOR HEALTH PROMOTION / PROGRAMME			
OPPORTUNITIES FOR HEALTH PROMOTION / PROGRAMME			
CHALLENGES TO HEALTH PROMOTION / PROGRAMME			

RESOURCES NEEDED:
- Flipchart paper
- Pens
- Camera
- Audio recorder
- Consent forms

CASE STUDY

TRANSECT WALKS WITH COMMUNITY LEADERS IN NIGERIA TO SUPPORT NTD PROGRAMMES
(BY NOELA GWANI ON BEHALF OF COUNTDOWN)

COUNTDOWN
Calling time on Neglected Tropical Diseases

Transect Walk

The aim of the transect walk was to identify community structures used for MAM activities and to identify potential structures that could be used in the future. This was one of COUNTDOWN's research methods, used by researchers and co-researchers working together for data collection in selected communities. I was part of the team of researchers who conducted transect walks in Kaduna, Nigeria in a range of communities which were comprised of a mix of different cultures and religions. Before we began the walk, the research team met with some community

leaders with the help of a health worker from the health facility. We explained the purpose of the activity to the community leaders and asked for their consent. Once consent was granted, we started to recruit participants for the walk. Leaders from different community groups volunteered to join the walk, and helped to identify major roads or areas in the community where the transect walk would be conducted.
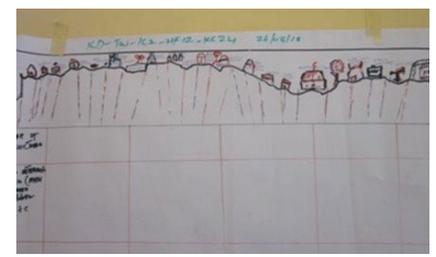
BENEFITS AND CHALLENGES

In our experience, transect walk participants were highly engaged and willing to share information and identify structures in their communities, enabling us as researchers to develop a good understanding of the communities, their customs and their local practices. The transect walk helped to raise awareness of the NTD programme; community members wanted to know the purpose of the walk and community leaders and researchers were able to explain that it was part of an NTD programme to improve MAM. The participants identified important structures such as the houses of the village heads, where advocacy visits take place, places where young people meet, and leisure areas for men.

Transect walks require time, as the walk often takes up to 30 to 45 minutes, then after the walk the sketching of the grid takes a lot of time and people sometimes lose interest. From our experience, the safety of participants was difficult to guarantee because of the high rate of insecurity. To address this challenge, community leaders informed community members about the activity and ensured that the walk only passed through a major street in the community, rather than through isolated areas.

TOP TIPS

Transect walks can be used as a method of community entry when starting a project in a community.

COMMUNITY / SOCIAL MAPPING

INTRODUCTION TO METHOD

Social Mapping is another method that can be used to better understand communities. There may be particular areas of interest where different groups within the community interact. For this method, community members are asked to create maps of the community using the materials they prefer, for example pens and paper or sticks and stones to map out structures on the floor. In order to understand how different knowledges and experiences of the community, researchers can ask different community groups such as youths, men, and women to each create a map, which can then be compared.

HOW TO DO METHOD

1. Identify important community groups to participate.

2. Obtain informed consent and provide appropriate materials to make the maps.

3. Ask the participants to draw a map of their community.

4. To support this process, the facilitator could ask questions such as:

- **What is located here?**
- **How frequently do people meet there?**
- **Who meets there?**
- **How long has this been there?**
- **Where do people collect water?**
- **Where do people collect firewood?**
- **Where do people pray?**
- **What social activities do people do? E.g. sporting, drinking etc.**
- **What times of day/year do people meet at specific places/complete specific activities?**
- **Where are the points and people of influence within the community located?**

5. Once the map has been drawn, the facilitator will use it as a point of discussion to understand how the health programme could better integrate within the community. Depending on the type of health programme, the facilitator could adapt the following questions:

- **Which of these community structures are important for health and wellbeing?**
- **If you could make changes to your community or parts of the community, what would they be? Can you show me on the map the things that you would like to change?**
- **How are the community structures you have identified currently used in the distribution medicines/vaccines/health promotion?**
- **Of the structures identified in your community map, which could be used as alternative structures to deliver the medicines/vaccines/health promotion?**
- **How might these different structures increase the reach of the health programme for specific community members such as those with disabilities, migrant populations, youths, women and men?**

6. The next step may be to bring different groups together and compare maps. This could create a space for dialogue and collective decision-making. Power dynamics are important to think about in these discussions and should be facilitated by a skilled facilitator.

RESOURCES NEEDED:

- Flipchart paper
- Pens
- Consent forms
- For discussion section: An appropriate environment which is safe, has enough space and limited distractions.

CASE STUDY

SOCIAL MAPPING FOR UNDERSTANDING MAM COVERAGE FOR NTDS IN NIGERIA
(BY SAMSON ABUBAKAR ON BEHALF OF COUNTDOWN)

COUNTDOWN
Calling time on Neglected Tropical Diseases

Social mapping can be used as a complimentary exercise to a transect walk. While transect walks involve key leaders identifying structures in a transect-like manner, often along a major road in the community, social mapping involves community members from different groups discussing and identifying broader structures in the community. Social mapping is also referred to as community mapping. Participants draw maps of the community which will provide an in-depth visual description of community structures. Though having a fine-looking map will be interesting, the aim however is identification of significant structures within a defined area that shows the interacting point of different groups of people in the society.

Kaduna state in Nigeria is endemic for Preventive Chemotherapy NTDs (PC-NTDs).The state has received financial and technical support for NTD activities for over 20 years, funded in large by Sightsavers, an NGO hosted in the urban and cosmopolitan Kaduna North LGA. However, coverage in the area has been low - two years before the commencement of COUNTDOWN research activities, less than 65% of the coverage target for MAM was achieved. Findings from the COUNTDOWN situational analysis shows that *'...community leaders and associated structures such as religious groups, village health committees and market associations were critical in shaping how communities responded to MAM'* (Adekeye et al., 2020). In order to enhance equitable MAM and inclusion, COUNTDOWN undertook social mapping with members of different socio-demographics, for example groups based on gender, culture, religion age, occupation, educational qualification.

Two focal communities were selected in Kaduna North LGA; one was characterised by high socio-economic status, good social amenities and low noise levels, while the other was an area of low socio-economic status, with high levels activity and interaction between community members. Interestingly, community drug distributors (CDDs) found it more difficult to access the high socio-economic status area.

We conducted four community mapping exercises in each of the communities, with 6-8 participants in each group. We had an older men's group, younger men's group, older women's and younger women's group, as represented in the table below.

GROUP	NUMBER OF PARTICIPANTS
Older men (31 years and above)	6-8
Older women (31 years and above)	6-8
Younger men (18 years - 30 years)	6-8
Younger women (18 years - 30 years)	6-8

The groups identified structures that were engaged in NTD activities, such as sensitisation and awareness campaigns, communications and administration of medicines. They discussed the challenges faced by these structures, and suggested ways that their functioning could be optimised to promote inclusiveness and equity in NTD activities. For example, participants identified potential structures that could be utilised in NTD activities but had not yet been engaged, as well as pointing out migrant routes and settlements that were often missed during MAM.

We guided the community mapping sessions with questions such as: What kind of activity is carried out there? What is the target group for the activity? What are the possible solutions to the challenges faced by this structure?

At the end of all mapping sessions, the four groups came together to compare and contrast their maps. While the groups often identified similar structures, they had different ideas on their potential utility; for example, younger women suggested that public boreholes, where people go to fetch water, could be a good location for sensitisation and mobilistation, while younger men suggested football viewing centres for the same activity.

Below are two quotes from MAM implementers:

'Increased awareness and acceptability of medicines due to proper community engagement. More structures were identified and used for MAM activities e.g. church was used as fixed post in Kaduna North LGA. Extensive community sensitisation about NTDs and MAM activities was carried out.'

Working group member

'Traditional leaders also participated during sensitisation. There was a use of local community entertainers which led to more Community members to participate during the sensitisation.'

Working group member

SEASONAL CALENDAR

INTRODUCTION TO METHOD

Seasonal calendars are a visual method which can be used to show transformation over time, or to map time-related activities and variation across a community. Timing of health programmes is very important, and if not considered in planning, can affect the coverage and acceptance of the programme. Seasonal calendars can be used within Focus Group Discussions (FGDs) as a tool to generate dialogue about timing of health programmes, and how they can be improved.

HOW TO DO METHOD

1. Explain the purpose of the activity and gain informed consent from participants.

2. In groups of 6-10, ask participants to draw a calendar.

3. Depending on the aim of the research, questions can be asked by the facilitator such as

   - **When is the best time to deliver medicines/vaccines/health promotion activity?**
   - **When are people away from the communities for farming/work/school/travel?**
   - **Who are the people away at this time?**
   - **When are religious or cultural festivals held within the community?**
   - **When is the wet season?**
   - **When is the dry season?**

4. As participants are contributing answers they can write on the seasonal calendar or place sticky notes

5. If permission is granted, discussions can be audio recorded and photos can be taken of the calendar to support documentation.

RESOURCES NEEDED:

- Flipchart paper
- Pens
- Consent forms
- Audio recorder
- Camera

PARTICIPATORY GEOGRAPHIC INFORMATION SYSTEM (GIS) MAPPING

INTRODUCTION TO METHOD

Participatory GIS mapping engages co-researchers in assessing the spatial distribution of landmarks and services according to their perceptions and knowledge (Paloma, n.d). The co-researchers use knowledge garnered from the local community through informal discussions and community walks (e.g. transect walks) to capture the human geography of the area (Norris, 2017). Participatory GIS can be used to map categories or landmarks, as well as compare the perception of community groups or stakeholders towards the spatial distribution of the landmarks. The process can be used to raise awareness on priority landmarks within a setting and the maps can be applied in decision-making processes.

HOW TO DO METHOD

1. Identify suitable co-researchers for the process. Consider power and positionality of co-researchers as this might influence the details on the maps provided (see case study on the next page).
2. Identify the most suitable method for data collection to develop the maps, for example, interviews, community walks and GIS application software (see case study on the next page).
3. Decide on which landmarks to map (e.g. schools, health facilities, faith centres, etc). This is usually dependent on the aims of the project, and the decision could be taken by co-researchers or in collaboration with the research team.
4. Train co-researchers on how to carry out the method, for example, how to carry out interviews or informal discussions with community members associated with landmarks; how to understand and locate geographical coordinates, how to use GIS application software, how to use cameras and recorders.
5. Facilitate the process of co-researchers identifying landmarks and locating their coordinates, taking photo images of the landmark, and having interviews or discussions with community members.
6. Discuss findings with the co-researchers and engage them in designing the map from the process.

RESOURCES NEEDED:

- A tool to locate geographical coordinates e.g. a geospatial map or GPS (Global Positioning System) device
- Cameras
- Audio-recorders
- Notebooks
- Pens
- Laptop computer

CASE STUDY

REMOTE GIS MAPPING OF INFORMAL SETTLEMENTS IN BANGLADESH
(BY WAFA ALAM AND IMRAN HOSSAIN MITHU ON BEHALF OF ARISE)

ARISE Bangladesh had a plan to do the GIS mapping physically by visiting study sites. GIS mapping helps in capturing, storing, checking, and displaying data related to different landmarks (health facilities, religious places, government buildings, educational institutes, entertainment spaces, markets, playgrounds) and services (housing, sanitation, water management) in selected study sites.

We had initially planned that two researchers from the ARISE Bangladesh team would physically visit study sites and collect GIS coordinates through transect walks, with support from co-researchers and community members. They also intended to carry out informal discussions with community members during the transect walks. However, due to the pandemic and countrywide lockdown it was not possible to do the map physically as per the original plan. We decided to use maps from different sources that were available online in order to identify service providers and households, and to create geospatial maps of the study sites. ARISE Bangladesh conducted a rapid research on COVID-19 in different urban slums in Dhaka city from March - April 2020 through phone interviews. During that period, we met some young people who were involved in activities helping their local communities. We suggested that our maps could be developed together with these young people, who would act as community co-researchers. These co-researchers helped to identify slum outlines, landmarks, and roads. We communicated with the co-researchers through social media platforms due to the COVID-related mobility restrictions. After discussions to assess the interest and willingness of these young people to work as co-researchers, one young man from an informal settlement expressed interest and helped us to co-produce a map. We published a blog describing our first experience of co-producing GIS maps remotely.

Inspired by the success of our first experience, we approached more young people at planned community events in all three study sites as potential co-researchers. A woman and a man from the two other study sites expressed interest, and our research team members provided them with a brief orientation on creating GIS maps using a mobile app. We asked them to identify another interested young person from their community that they could pair with during the mapping process. As the initial co-researcher could not continue the mapping exercise due to time constraints, we requested that he help us to find to other potential co-researchers from his area. We ultimately recruited six co-researchers, one woman and one man from each study site. Each pair of co-researchers were given a one-day training session on the basics of GIS mapping and the mobile app used for collecting photos and location coordinates. In addition to the theoretical training, hands-on training on the Mobile data collector (MDC GIS) app was given. After the hands-on training, co-researchers collected GIS coordinates of important locations, infrastructure and roads in their area of informal settlement, and shared data from their mobiles to the project's GIS cloud account.

WHAT WERE THE BENEFITS OF THE METHOD/APPROACH?

- Identifying locations and infrastructure important to the community (including through photography and narratives).
- Co-production of the digital maps of informal settlements which the community can also use for their decision-making.
- Helps improve relationships with the community people.
- Strengthens capacity of the researchers and co-researchers.
- Increases accessibility to the community.

WHAT WERE THE CHALLENGES OF THE METHOD/APPROACH?

- As co-researchers are actively engaged with different activities, it was hard to manage their time during the data collection procedure.

- Using the GIS mapping software was new for the co researchers, so it took time for them to learn and get used to the software and its different features.

- The content of the training session needed to be modified several times to make it understandable for co-researchers.

- Different co-researchers had different needs; some co-researchers expressed capacity development needs that were beyond the scope of the ARISE team to provide. Others shared problems they faced in the community that we were unable to intervene in or solve.

- All of our co-researchers were youths, so there were times when older and more powerful members of the community created obstacles for their work and viewed them with suspicion.

- When co-researchers were mapping the most marginalised households in their area, some community members thought the co-researchers were part of a local non-governmental organisation (NGO) and expected help (cash/food assistance). When the co-researchers explained the purpose of the activity, many community members refused to participate e.g. to give permission to collect coordinates or take photographs of their house.

HOW DID WE ADDRESS THE CHALLENGES?

- It is important for researchers to be flexible with the availability of co-researchers, as they would only be able to send the coordinates at their convenient time.

- Multiple training sessions and refresher trainings were given to the co-researchers.

- Immediate assistance was provided over the phone if co-researchers faced any problem regarding the mapping procedure.

- Regular communication and follow-up sessions with co-researchers helped to address many of the challenges. We established an environment were co-researchers could reach out to us at any point (over the phone) to discuss issues they were facing in the community. As well as reflexivity meetings, we also conducted follow up/check-ins to ensure that the work was running to schedule e.g. whether co-researchers were sending photos and audio regularly.

- Weekly reflective sessions with co-researchers also helped to discuss their challenges and find a way to mitigate the challenges.

TOP TIPS

- Since the use of GIS applications/software is highly technical, it is helpful if the training modules/sessions designed for co-researchers are simplified and the training is provided in multiple smaller sessions.

- Refresher trainings will be useful.

- On the spot immediate troubleshooting and assistance may be required, and helps to build trust with co-researchers and establish a relationship where they know researchers are available to assist them when required.

- Weekly reflexivity session with individual teams are helpful where teams can discuss the different challenges and learnings from the process and it is useful to document these sessions.

- Monthly reflexivity sessions with co-researchers from all sites can act as a cross-learning platform and help them learn from one another, and exchange their ideas.

2.2 UNDERSTANDING COMMUNITY PERSPECTIVES AND LIVED REALITIES

This section looks at a variety of creative participatory methods, including a focus on visual methods such as photovoice, photo diaries, illustrations, and storytelling to understand community perspectives and lived realities. In this section you will:

✅ **Be introduced to and provided with step by step instructions on conducting participatory methods, either for data collection or dissemination**

✅ **Learn about case studies, which have used specific methods**

✅ **Consider the strengths and challenges of these methods**

✅ **Learn top tips for each method**

PROBLEM TREE ANALYSIS

INTRODUCTION TO METHOD

A problem tree analysis (PTA) or simply problem analysis is a method that uses the structure of a tree to map out the root causes and effects of an identified problem, and the wider factors that may contribute to aggravating or resolving the problem.

Problem trees are useful to apply in a planning process of a participatory research cycle because:

✅ **They explore potential sources of problems and find potential resolutions. The problems can be broken down into simple and manageable parts which can be prioritised in relation to the objectives of the project or research.**

✅ **The central issue can be identified and the interconnections between the other issues can be understood. This helps establish which actors to engage in solving the problem.**

✅ **They help differentiate between present problems that need action and problems of lower priority.**

✅ **They help to engage all actors of the project in a sense of common understanding, purpose, and action.**

HOW TO DO METHOD

1. Identify the problem: A problem can be any issue the group feels passionate about - it can be broad as the problem tree will break it down.
2. Write down the problem on a flipchart such that it becomes the trunk of a tree.
3. Identify causes of the problem and write them down as the roots of the tree. Give room for dialogues so that direct causes of the problem become the roots while wider causes become the surrounding soil. Wider causes include social and environmental factors and the political atmosphere of the context in which the problem is found.
4. Identify the potential consequences of the problem and write them down as the branches and leaves of the tree. Give room for debate and classification of the consequences such that direct consequences of the problem become the branches of the tree while secondary consequences and long-term impacts become the leaves of the tree.
5. Discuss potential solutions to the causes, which can be covered in responding to the following questions:
   - **Which causes are of urgent or major concern? What is the way forward?**
   - **Which causes are easiest to handle and which ones require more effort and resources to resolve?**
   - **What are the available human, financial and other resources that can be employed in solving the solvable problems?**
   - **What will be the plan of action of the team?**

PROBLEM TREE:

EFFECTS/CONSEQUENCES
- Direct consequences
- Indirect consequences and long-term effects

THE PROBLEM

CAUSES
- Direct causes
- Wider determinants: social, economic, cultural and political
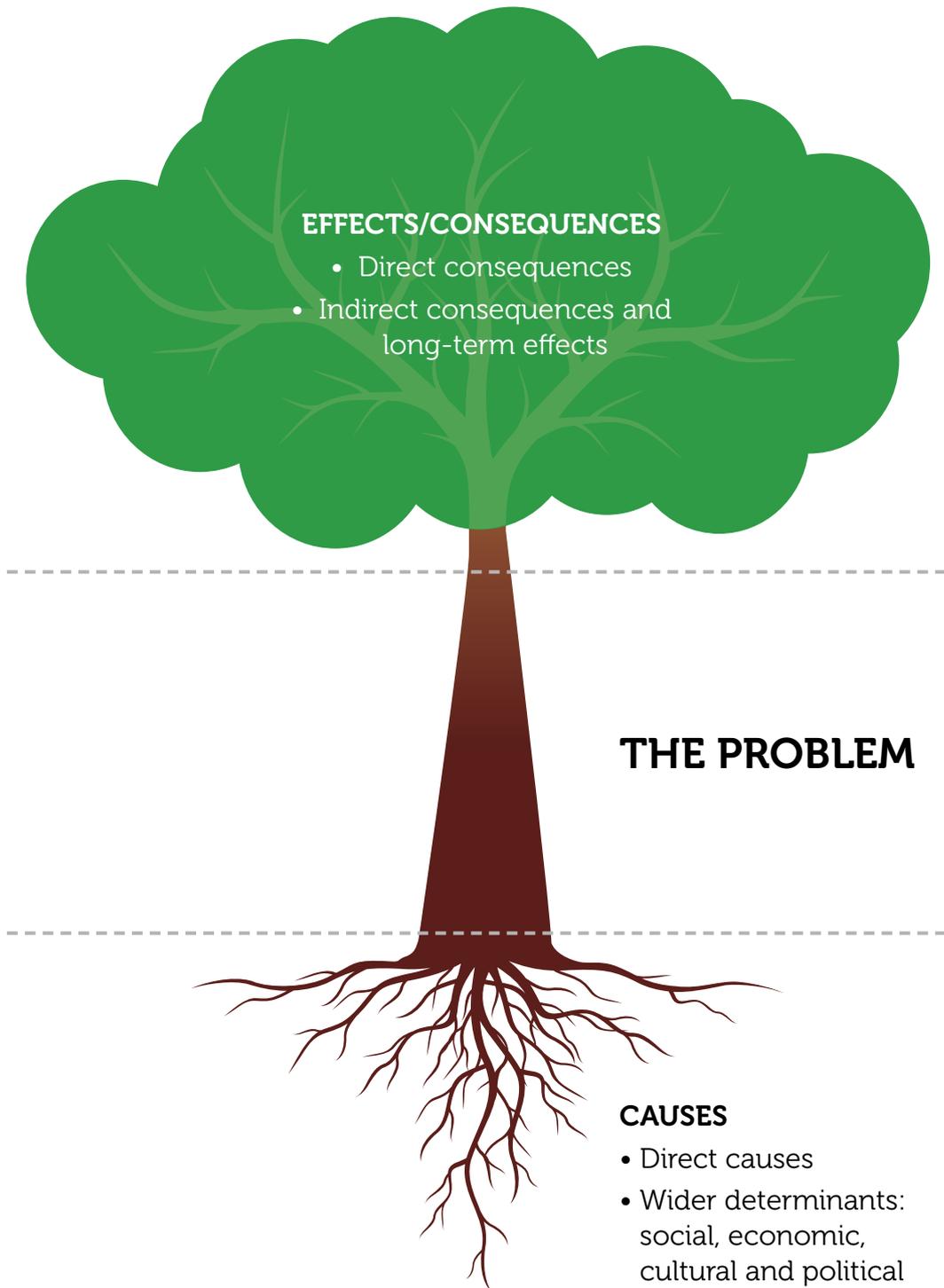
Problem Tree Analysis

RESOURCES NEEDED:
- Flipchart papers
- Pens
- Stick-on notes

CASE STUDY

PROBLEM TREE ANALYSIS IN IMPLEMENTATION RESEARCH FOR NEGLECTED TROPICAL DISEASES
(BY JAMES YASHIYI ON BEHALF OF COUNTDOWN)

In Ogun state, Nigeria, PTA was one among the qualitative methods adopted in the community engagement process to answer parts of the COUNTDOWN research questions. We engaged men and women who were absent during MAM and those who persistently refused to take the medicines during previous treatment cycles. Each participant was asked to reflect on reasons for their absenteeism or persistent refusal to swallow the medicines. In both rural and urban contexts, participants were selected using the NTD community register obtained from the health facility overseeing the selected communities.

PTA is represented by three basic components of a tree: the roots, trunk and the leaves. While in the case of our study the **roots** symbolise causes of absenteeism or refusal to take MAM medicines, the **trunk** symbolises the problem, which is "accessing and taking the MAM medicines when they are brought to the community". The **leaves** symbolise consequences of taking or swallowing the medicines when made available.

THE PROCESS

We researched causes and consequences of the problem of accessing and taking the MAM medicines in two communities. Participants were separated into groups by gender (men and women), in order to understand any gendered factors that might have been contributing to the problem.

A tree was sketched on a flipchart. Firstly, participants wrote down perceived causes of the problem on sticky notes and stuck them to the roots. They then wrote down consequences and stuck them to the leaves.
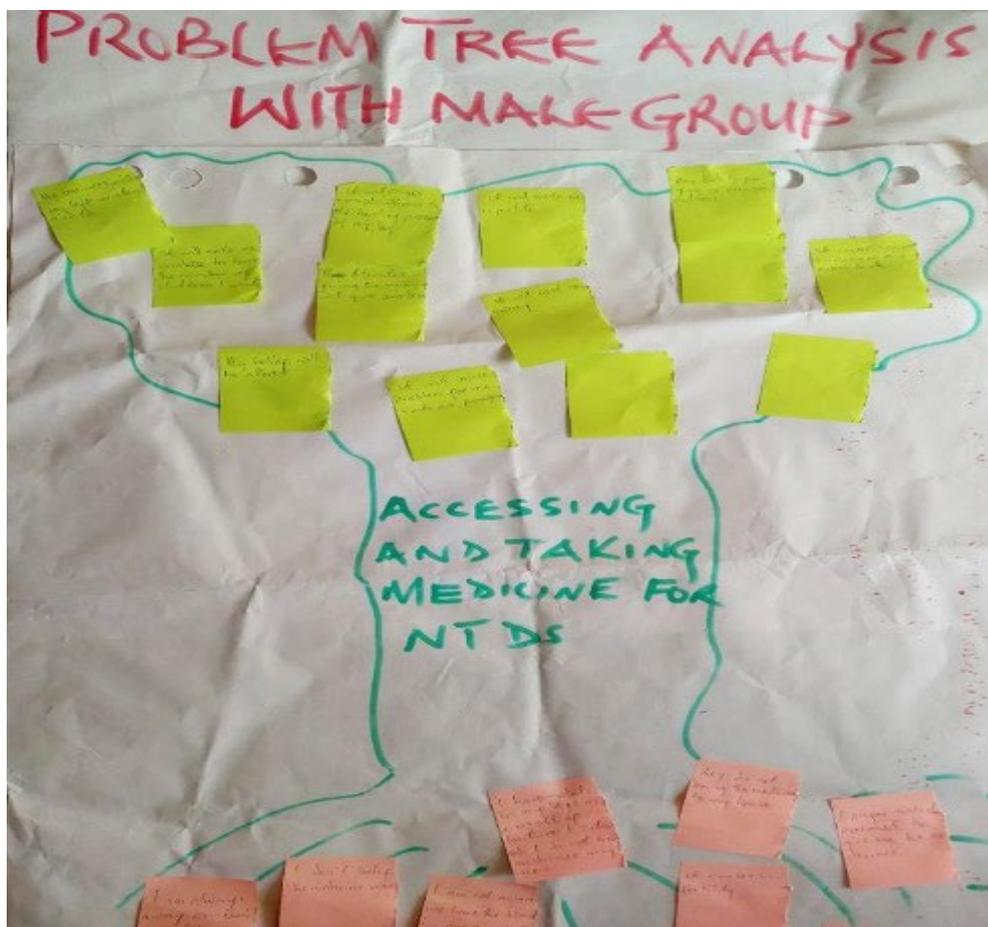
Diagram from PTA with male persistent refusers in a community - Urban context, Ogun. Conducted in November 2018.

WHAT WE FOUND

Among male persistent refusers, causes included rumours about the medicines causing infertility, disbelief about the presence of the NTDs in the community and disbelief about efficacy of western medicines compared to traditional medicines. Perceived consequences included medicine consumption leading to infertility, or the inability to have a number of children desired.

Among female persistent absentees, causes mentioned included fear of menstrual cycle disruption and infertility, beliefs from husbands and family members against the use of western medicines, absence from home due to business engagements and religious beliefs. Consequences included disruption of menstrual cycles and eventual infertility, side effects such as cancer which were associated with western medicines, business losses and disharmony within marriages and family relations if their husbands felt their beliefs were not respected.

While discussing solutions to persistent refusal, some male participants recommended greater sensitisation about the safety of the medicines. They suggested that this sensitisation should not only be disseminated on the radio and television but also by religious clergies. Others stated that medical doctors should be encouraged to talk to their patients about the efficacy of NTD medicines when they go to hospitals for routine medical attention. Participants suggested that MAM should be a national programme, enabling people to access medicine from anywhere in the country, not just in their location of residence.

BENEFITS OF THE METHOD

This body of evidence from PTA was triangulated with other qualitative methods to produce recommendations for inclusive planning of MAM, as contained in the Participatory Guide for Planning (PGP) equitable Mass Administration of Medicines. The PGP document emphasises a context-specific and bottom-up approach in engaging with different segments of communities such as women, migrants, and other marginalised groups. The document is used to develop effective strategies for all aspects of MAM such as action planning, training, medicines logistics and distributions, to meet specific needs and solve 'problems' associated with the NTD programme.

VIGNETTES

INTRODUCTION TO METHOD

Vignettes are short stories about a hypothetical person, which can be presented to participants during qualitative research to gather information about their beliefs. They are usually developed from previous research or examples of situations which reflect the local context, creating a story that participants can relate to. Participants are typically asked to comment on how they think the character in the story would feel or act in the given situation, or what they would do themselves. Vignettes can help in redressing power dynamics within the group as it emphasises the value within participant narratives as opposed to prioritising the voice of health systems implementers.

HOW TO DO METHOD

1. Develop a short story, related to a character, developed from findings that cover main themes.

2. Ensure name of people and diseases in stories are local names, validate with country teams and participants.

3. Read vignettes out loud in small groups and ask questions around main themes.

   Questions can include:

   - **What are the main messages from the story?**
   - **How does this person's story relate to your own experience/how does it differ, or how you would do things differently?**
   - **What are the strengths and weaknesses highlighted in this story?**

4. Note down responses on flipchart.

> **RESOURCES NEEDED:**
> - Printer/Laptop to view vignettes
> - Flipchart papers
> - Pens
> - Stick-on notes

CASE STUDY

USING VIGNETTES TO EXPLORE ACCESS TO CASE MANAGEMENT OF NTDS IN LIBERIA
(BY SHAHREEN CHOWDHURY ON BEHALF OF COUNTDOWN)

COUNTDOWN
Calling time on Neglected Tropical Diseases

This study took a CBPR approach, with the research aim of improving access to health services for people affected by NTDs in Liberia. In the reflection phase, we conducted 15 key informant interviews and 11 FGDs and 7 PWs with community and health system stakeholders to understand barriers to providing and accessing care for people affected by NTDs. Following analysis, the main themes from the findings were developed into short stories to present at a dissemination workshop in Monrovia with key stakeholders. We used four vignettes to illustrate key strengths and weaknesses in NTD case detection, through the stories and perspectives of a Community Health Assistant (CHA), a Community Health Volunteer (CHV), a Community Drug Distributor (CDD) and a Patient.

The aim of vignettes was to bring out the voices of research participants and encourage discussion amongst stakeholders in the dissemination meeting. Participants were mixed and split into three groups, to read through the stories and fill in a table of strengths and weaknesses, highlighted from each story. By acknowledging the strengths and addressing the weaknesses of different case detection models in operation in Liberia, the groups developed recommendations of best practices. Each group then presented their findings to the whole meeting; this encouraged dialogue and enabled participants to reflect on similarities and differences.

STRENGTHS

- Vignettes were an effective way to synthesise a large amount of data, by drawing out key details from data.

- The stories resonated with stakeholders and prompted community health workers and health system stakeholders to add their own thoughts. For example, the supervisor confirmed findings regarding availability of drugs. The CHV also consolidated findings on the need for supervision; he used the metaphor of 'taking a test without receiving any results' as way of describing his work as a CHV without adequate supervision or feedback.

CHALLENGES

- It was a challenge to ensure that the stories adequately captured the key findings from the data. A process of validation helped to address this by asking participants questions such as *"How does this story reflect the findings? Is there anything else you would add?"* This prompted rich discussions amongst participants and the research team as the vignettes served as another way to critically reflect on the findings.

- This activity exceeded the allocated time and towards the end, participants began to get tired. In hindsight, the vignettes should have been shorter, and the CHV/CDD story could have been collapsed into one as they had similar themes. Working in smaller groups and using ice breaker activities helped to keep participants engaged.

- Considerations should be made to avoid particularly sensitive and emotional aspects of a vignette, especially when in the presence of patients or affected persons. Issues around stigma are sensitive and should be represented in respectful ways so that stories are not exaggerated.

TOP TIPS

Ensure vignettes are relatable and context specific. Drafts of the vignettes were shared with the Liberian research team to ensure that the stories were written in cultural and context specific language for Liberian names of diseases.

- Avoid lengthy stories to keep participants engaged.
- Use a process of validation to check with participants whether the stories captured the main themes.
- Sensitive topics should be represented in respectful ways, avoid exaggerations and ensure stories do not identify particular participants within the study.

Vignettes being read by stakeholders in Dissemination Meeting, Monrovia, 2019

'My name is Boimah and I am 41 years old. I have everlasting sore (Buruli ulcer) but it took me a long time to get diagnosed ...I used to take part in the community but now I mostly stay alone. My wife got frustrated because I can't work anymore, and I cannot afford to pay for my children to go to school. Some people fear if they stay near me, they will get the disease. I feel very alone in my illness.'

Excerpt from Patient - Vignette, Liberia Study

USING VIGNETTES WITH INFORMAL HEALTH PROVIDERS IN LIBERIA
(BY ROSALIND McCOLLUM ON BEHALF OF REDRESS)

Vignette discussion group with traditional healers in Lofa County

BACKGROUND AND CONTEXT

Within Liberia, many people seek care from informal health providers for a range of reasons. These can include cost barriers with seeking care at a health facility (although health care is free, drug stockouts are common and patients may be given a prescription and need to seek drugs elsewhere as a result); distance to health facility; trust in providers closer to their own community and beliefs around the causation of illness. In particular, many SSSDs are thought to occur due to supernatural reasons. As a result, people affected by SSSDs often experience stigma, isolation and discrimination within their communities. Spiritual beliefs are influential in determining where care is sought.

We sought to understand more about management processes for patients presenting with symptoms of SSSDs, among 43 of the most common informal health providers (traditional healers, black baggers and faith healers) in two counties in Liberia (Grand Gedeh and Lofa County). In order to understand these practices, we chose to use the vignette methodology.

WHY USE VIGNETTES?

Vignettes provide a helpful methodology to explore topics which require mindfulness and sensitivity. Within this study the vignettes used different scenarios with informal health providers to explore how they currently manage patients and respond in certain situations. Each group was presented with different scenarios using vignettes of patient stories or experiences, e.g. a patient who was seeking care and experienced symptoms of leprosy, or a person with an SSSD who expressed suicidal ideation. The group then discussed what they would do in the situation, how they would respond and what treatment they would recommend or provide.

WHAT ARE THE BENEFITS OF USING VIGNETTES?

Using a vignette was an effective way to prompt discussion among informal health providers. Most participants actively engaged in the discussions and were willing to share how they would support or manage the patient scenarios.

Due to the fact that black baggers (informal medicine sellers) are not officially permitted to treat patients within Liberia, they expressed some hesitancy about participation. Using a vignette was a more acceptable form of engaging with them and seeking to understand how they provide care.

Vignettes provided an opportunity to use oral storytelling to prompt discussion. This can be of value within communities where storytelling is appreciated. It is also a suitable methodology to use with participants who may be visually impaired. For example, in one of the groups one of the participants was blind, but appreciated having the opportunity to contribute fully to discussions.

WHAT ARE THE CHALLENGES WITH USING VIGNETTES?

For the discussion around the vignette to be most useful, the vignette needs to be developed so that it is suitable and easily understood by participants. For our study vignettes were based on examples of case histories of people affected by SSSDs collected in an earlier study.

Due to the sensitive nature of some topics, recruitment may be challenging, with clarity needed to ensure that participants invited are suitable for inclusion and willing to take part.

Similarly, due to the sensitive nature of topics, we found that black baggers in one county were reluctant to openly discuss and share their experiences. This group needed prompting and skilled facilitation to build confidence for participants to discuss the vignette more extensively.

Participatory methods may highlight issues that researchers are not aware of. In some instances, this can mean that negative practices are highlighted. Reflecting on negative practices together with co-researchers to avoid further stigmatising people affected is important for the best practice of participatory methods.

TOP TIPS

- If possible, develop vignettes based on prior research in order to ensure that they are appropriate to the local context and participants.
- Pilot test vignettes to ensure that participants have clear understanding about the story and to develop probing questions to explore this more.
- Vignettes are often used as a way to prompt discussion sensitively, and so depending on the topic areas, may need strong facilitation skills.

ILLUSTRATIONS

INTRODUCTION TO METHOD

Illustrations, including drawings and cartoons, are creative participatory methods in health research recognised as an engaging way of presenting findings. This method uses drawings to highlight key issues or ideas for solutions. They can be particularly effective in generating discussions around sensitive topics. These pictures are open to interpretation, so it is important to follow up with dialogue.

HOW TO DO METHOD

1. Create a drawing to depict a scenario/context; this can be drawn from findings if used in dissemination. A local artist can be engaged to produce images.

2. If facilitating participatory drawing by participants around a topic, emphasise that the purpose of the drawings is not based on artistic skills but on expression.

3. Use drawings to highlight key issues or ideas for solutions. These pictures are open to interpretation.

4. The pictures can be used in group discussions to discuss the meanings behind them.

   Questions can include:

   - **How do the pictures differ from or reflect the participants own experiences and thoughts?**
   - **What issues have been highlighted? What can be done about them?**

RESOURCES NEEDED:

- Paper
- Coloured Pens/Pencils/Paints/Crayons OR Local artist
- Flipchart

CASE STUDY

DISSEMINATING FINDINGS ON NTD CASE MANAGEMENT IN NIGERIA USING CARTOONS
(BY SHAHREEN CHOWDHURY AND MARTINS IMHANSOLOEVA ON BEHALF OF COR-NTD, SIGHTSAVERS AND LSTM)

This is a case study of our experience in Nigeria using cartoons in dissemination and intervention design to improve case management for people affected by NTDs. We used a CBPR approach, 53 data points were collected including 17 illness narratives, 12 in depth interviews with household members, 12 FGDs with CHWs, 6 FGDs with primary health workers and 6 FGDs with secondary health workers. Our research team involved people who were affected by NTDs and community health workers as co-researchers.

Following thematic data analysis with our co-researchers, core themes were generated from the data. We thought about creative and inclusive ways of presenting data. We decided to use cartoons to conceptualise the main themes along the Lévesque patient pathway (Lévesque et al., 2013), which highlighted both patient and provider perspectives in accessing care. A local artist based in Nigeria drew these cartoons based on the findings, which powerfully highlighted factors affecting the care seeking pathway. This included stigma affecting the ability to seek care, loss of income in the ability to pay for care and also the burden on health workers of being able to provide appropriate care.
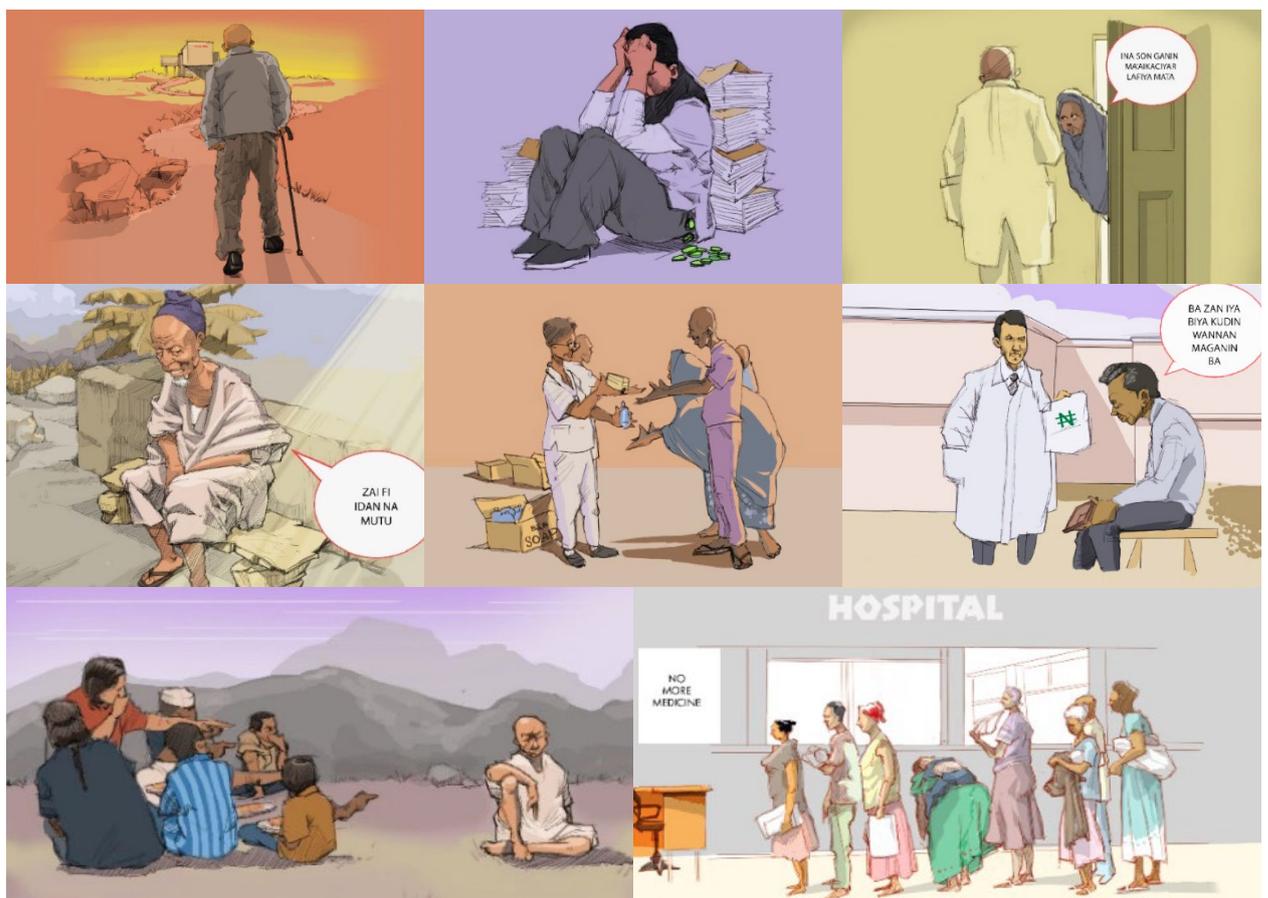
Cartoons developed from findings from co-researchers. *Credit: Christian Okwananke.*

A one-day dissemination workshop was conducted in Abuja with stakeholders, including programme planners and implementers at both national and state levels, and the co-researchers. The cartoons were used to disseminate and validate key messages and learnings from the data. We presented the cartoons across a wall following the Lévesque pathway to encourage an interactive space for dialogue and discussions amongst all participants.

The cartoons were so well received by stakeholders that they decided to develop them as part of the intervention, which included posters and digital flip books used to increase awareness of NTDs, stigma and the importance of early case detection for health workers and community members. These cartoons were also taken forward and adapted by the Federal Ministry of Health to deliver COVID-19 health messages.
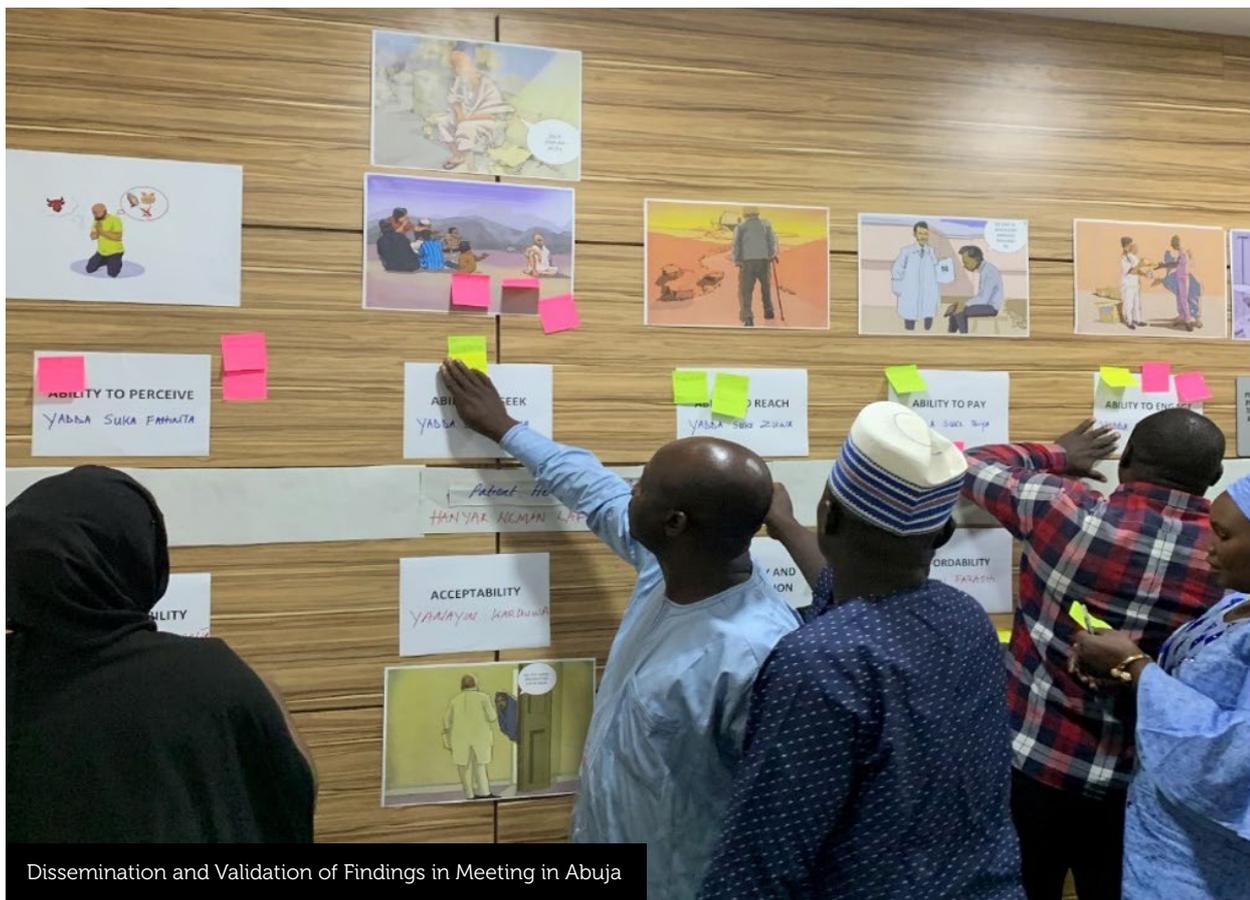
Dissemination and Validation of Findings in Meeting in Abuja

THESE METHODS:

- Fostered the uptake of research findings into interventions which were responsive to priorities highlighted by people affected, such as in health messaging in digital flipbooks and posters.

- Created an equitable and collaborative space for learning amongst all participants.

- Helped to discuss sensitive topics, such as stigma and mental wellbeing.

- Prevented the depiction of people affected as passive victims or sufferers, as is often the case with photography, allowing for abstract presentations of lived experiences.

TOP TIPS

- Remember that creating cartoons is an iterative process.
- Ensure images are context and culturally specific.
- Validate images with co-researchers.

PHOTOVOICE

INTRODUCTION TO METHOD

Photovoice is a creative participatory methodology, which aims to empower participants to take ownership of presenting their own narratives (Kindon et al., 2007). The method was developed by Wang and Burris (1997) from their research with women in rural China.

The photovoice process involves participants taking photographs within their communities to capture their experiences and daily realities (Wang, 1997, Budig et al., 2018). The photos are followed up with a discussion to capture verbal accounts of what photographs represent and to contextualise the visual images. Images are then selected to be presented and discussed within group discussions. Some photos are further selected to share in dissemination workshops, designed to develop solutions to challenges identified and or to raise awareness of issues described in participant photo narratives.

HOW TO DO METHOD

(Adapted from Ronzi et al., 2019)

1. Train participants on taking photos and brief them on the themes of research.

2. Ask participants to take photographs in their community relating to the main themes of the research, over a period of time agreed by participants and the research team.

3. Conduct individual interviews with each participant to discuss the meaning of the photographs.

   Questions developed from the SHOWeD acronym (Wang and Burris, 1997) can be used:

   S What do you **S**ee here?

   H What is really **H**appening here?

   O How does this relate to **O**ur lives?

   W **W**hy does this situation, concern or strength exist?

   e

   D What can we **D**o about it

4. Ask participants to pick **10-20** key photos that present themes.

5. In groups, ask participants to present key photos and summarise their meanings. With the participants, choose photos to be displayed and check the captions.

6. Share the photos in an exhibition with stakeholders.

RESOURCES NEEDED:
- Cameras
- Batteries
- Printer/Laptop to view photos
- Flipchart papers
- Pens
- Stick-on notes

CASE STUDY

USING PHOTOVOICE WITH COMMUNITY HEALTH PROVIDERS IN LIBERIA
(BY ROSALIND McCOLLUM ON BEHALF OF REDRESS)

REDRESS
Reducing the burden of
Severe Stigmatising Skin Diseases

Photovoice participants during initial training in Lofa County included photovoice, consent, photography

Three one-on-one discussions were held with participants over a three week period

BACKGROUND AND CONTEXT

Within Liberia, many SSSDs are thought to occur due to supernatural reasons. As a result, people affected by SSSDs often experience stigma, isolation and discrimination within their communities. Spiritual beliefs are influential in determining where care is sought. Community health providers, such as traditional healers, faith healers, community health assistants and CHVs all play strong leadership roles at the community level and enjoy trusting relationships with community members. This trust enables them in their roles, for example CHAs and CHVs can enter people's homes as part of active case finding for SSSDs.

WHY USE PHOTOVOICE?

REDRESS uses PAR approaches by listening to and involving co-researchers and using participatory methodologies. Photovoice involves participants throughout the research process with co-researchers informing priority areas for study and involved in data collection and analysis. We involved 30 participants (CHAs,

Participants came together in their participant groups to group photos into themes

CHVs, traditional healers and faith healers) from two counties (Lofa County and Grand Gedeh County) within th REDRESS photovoice project. While the work of traditional healers and faith healers is often misunderstood from a biomedical perspective, photovoice enabled REDRESS to work with community level health providers as co-researchers,to deepen our understanding of the roles they play within their communities. It also provided scope to jointly identify actions to improve identification and holistic care for people affected by SSSDs.

Booklets have been developed from the study and it is planned that these will be used as part of dissemination to develop a wider understanding among biomedical decision-makers of the unique role which these community providers play in caring for people with SSSDs.

WHAT ARE THE BENEFITS OF USING PHOTOVOICE?

Participant groups discussed photo themes and possible actions together

We found that using photovoice provided opportunity for community health providers (some of whom had limited literacy) to actively engage with the various stages of the research process. It enabled them to identify the important aspects of their roles, their challenges, and motivations and to reflect together as a group to identify common themes. It also helped to develop shared learning and understanding, and to identify critical actions to improve care for people affected by SSSDs.

After the sessions were completed, participants themselves reflected on their deeper awareness of the challenges faced by people affected by SSSDs, particularly the social impact occurring because of stigma and discrimination. Community health workers, including CHAs and CHVs highlighted that photovoice had allowed them to step back from their usual roles and to observe the changes that they have brought to their community. Many found this recognition of their hard work very encouraging. Co-researchers also appreciated the photography skills which they gained through the study.

WHAT ARE THE CHALLENGES WITH THE METHOD AND HOW WE ADDRESSED THESE?

We identified four key challenges with using this method, described below:

1. Managing co-researcher expectations is a key aspect of photovoice research. It was important that initial training held with participants highlighted the purpose of the study, along with realistic expectations for what the study and related actions could achieve.

2. Discussing the consent process around taking and using photographs was critical, particularly as people affected by SSSDs often experience stigma and may not be reluctant to be photographed. It was very important to avoid coercion by co-researchers. Emphasising the critical nature of consent with co-researchers during training was vital and was re-visited throughout the study.

3. SSSDs are frequently stigmatising and so it is important that those who consent to be photographed are not further marginalised as a result of their participation. Throughout the analysis process this was considered, with some photographs excluded or faces blurred to prevent potential stigmatisation of the person affected.

4. Participatory methods by their nature highlight issues not previously known. In some instances, this can mean that negative practices are highlighted. For example, at times some of the participants used terms to describe mental illness which could be considered stigmatising. Reflecting on negative practices together with co-researchers to avoid further stigmatising people affected is important for participatory method best practices. This will be an important step in the next stage of the study where we will identify interventions to improve care for people affected.

TOP TIPS

- Photovoice can help to inform action but will not directly solve problems, so it is important to manage expectations from the start of the study.
- Reflect on the importance of informed consent throughout the study.
- Think in advance about what you will do if your study highlights 'negative practices' and have safeguarding protocols in place if needed.

THE USE OF PHOTOVOICE IN DEVELOPING SUPPORT GROUPS FOR PEOPLE AFFECTED BY STIGMATISING SKIN DISEASES IN NIGERIA

(BY SHAHREEN CHOWDHURY AND OLUWATOSIN ADEKEYE ON BEHALF OF COUNTDOWN)

Co-researchers leading training on photovoice

This study used a CBPR approach to explore wellbeing and psychosocial support for people affected by NTDs. The aim of the study was to design support groups in collaboration with people affected by NTDs, and the photovoice method was used to identify core issues and themes to be addressed in the support groups. It was also used to establish relationships and connections between people affected by NTDs.

Co-researchers, including people affected by NTDs, were recruited as part of the core research team. The process involved training of co-researchers on photovoice, including the use of cameras and ethics of photography. Co-researchers have then supported other people affected by NTDs, and caregivers, to become familiar with taking photos. We decided to focus on caregivers as well as people affected by NTDs, because caregivers are often impacted by NTDs but rarely considered within interventions. Within this CBPR study, co-researchers were involved in all stages of the research from data collection, analysis and the development and evaluation of the support groups.

After participants were trained on the steps of photovoice, they were asked to take photos to document their experiences of wellbeing and stigma over 2 weeks. As participants and co-researchers shared their photos, they had one on one discussions with the research team to describe the context behind their photos. They were then asked to pick 10-20 key photos to share in a group discussion.

Within group discussions, participants shared and analysed their photos into key themes, and captions were forumulated by participants to ensure they had been accurately represented. These key photos were developed into photo booklets, which showcase the photos, and aim to show the realities of people affected by NTDs through their lens, and focus on multiple themes including stigma, psychosocial wellbeing and support. The photo booklets cab be viewed here:

🖱 **Kaduna Photovoice Booklet:** countdown.lstmed.ac.uk/sites/default/files/centre/COUNTDOWN%20 Kaduna%20Photovoice.pdf

🖱 **Kwara Photovoice Booklet:** countdown.lstmed.ac.uk/sites/default/files/centre/COUNTDOWN%20 Kwara%20Photovoice.pdf

We then presented the photo booklets and photos in an exhibition which brought together participants, co-researchers and other stakeholders within the State ministries of health to design support group interventions based on the emerging findings from the photovoice.

Photo Exhibition and Intervention Design Meeting

We found that images are effective as they can be understood beyond literacy levels, and amongst different cultures and languages. As co-researchers and participants shared their stories through their photographs, many stakeholders, such as the State programs resonated with a lot of the images and this sparked discussions around how to address challenges identified through photovoice.

Establishment support groups, led by persons affected

Wellbeing and mental health is often "something not openly seen". However, photos representing various aspects of wellbeing sparked conversations amongst participants and allowed discussions and deconstructions around perceptions of wellbeing and stigma. Many co-reserachers reflected on how photovoice allowed them to express emotions. The photos highlighted challenges and encouraged co-researchers to lead discussions on how they could be addressed within the design of support groups, which focus on health information, training on wound care, psychosocial support and vocational training.

TOP TIPS

When conducting photovoice it is important to consider the following:

- Assess the knowledge base of potential participants: where participants are in the rural areas, it is important to first build rapport with the participants. This is critical to the engagement process.
- Assess what participants know about the use of cameras or phones as this will help in the design of the training program.
- Train participants in the use of all functions of the camera.
- Assess availability of electricity to determine what kinds of cameras would be used, and the probable need to provide extra batteries.
- Consider the participants' basic understanding of the topic being researched, so that appropriate pictures can be taken.
- Organise weekly review meetings with participants to ensure that photographs taken are relevant to the topic of the research.

CASE STUDY

USING PHOTOVOICE TO UNDERSTAND THE VULNERABILITY AND EMPOWERMENT OF FEMALE SEX WORKERS IN MALAWI
(BY WEZZIE LORA)

My research focused on understanding the vulnerability and empowerment of female sex workers (FSW) through engagement with HIV self-testing (HIVST) in Malawi. I employed photovoice as a data collection method to capture the needs, aspirations and lived experiences of FSW, as well as the complex, multi-layered realities of their lives in the context of HIVST.

The photographs taken by participants illustrated their lives and what they hoped for in the future, encouraging personal reflexivity and the expression of emotions. In this context, participant-generated visual data were beneficial as a means for FSW to make sense of their past, present and prospects for the future. Photovoice was valued as a methodology for understanding the social world through the lenses of those experiencing it.

FSWs are a stigmatised population in Malawi, and I was concerned that photovoice implementation might exacerbate their preexisting vulnerability in their communities. Training helped to mitigate these challenges and to build relationships between FSWs and the researchers. For example, we encouraged FSWs to use symbolism rather than to take images of people's faces or personal identifiers, to maximise confidentiality and mitigate potential safety issues. FSWs reported enjoying being valued for their insights and contributions to the research, and seeing the impact that the photovoice process had in their respective communities. Photovoice gave FSWs a diverse opportunity to interact with community members and to be seen through a different lens than the usual lens of sexuality. Our partnership with FSWs enhanced the good rapport and trust during the photovoice activity. As a result, we could interact with FSWs in different ways; at some points, FSWs were our teachers, leading us into their lives through their photography and discussion, while at other points they needed our guidance, particularly around the technicalities of using the cameras. This reversal of normal power dynamics helped to strengthen the relationship between FSWs and the research team, which was maintained after the photovoice activity had finished.

Participatory research methods like photovoice are rarely used with FSWs and there is a risk that adopting these strategies can lead to further marginalisation of this group. Participatory research methods with FSWs are important if global control of the HIV epidemic is to be achieved. On both public health and human rights grounds, views and insights from FSWs can facilitate the expansion of feasible and culturally appropriate HIV prevention, treatment, and care to FSWs, even in rights-challenged environments.

PHOTO DIARIES

INTRODUCTION TO METHOD

Photo diaries are a useful tool/method for identifying health and wellbeing needs and understanding, experiences and challenges of communities. Particularly for marginalised individuals or vulnerable communities, who often do not have a voice or platform to advocate their needs, these photos along with the narratives collected from their lived experiences serve as evidence for identifying potential actions for change, and for advocacy. Photo diaries can be useful especially as a remote method.

HOW TO DO METHOD

1. Provide recruited participants with a camera, or ask them to use their existing device (e.g. smartphone)

2. Ask participants to photograph anything in their community or routine lives that relates to either a challenge or a support/asset in obtaining good health and wellbeing.

3. Use photographs to guide narrative interview sessions with each participant to explore particular images and places and their meanings.

> **RESOURCES NEEDED:**
> • Camera or smart phone
> • Recorder

CASE STUDY

PHOTO DIARIES AS A REMOTE METHOD FOR EXPLORING HEALTH AND GOVERNANCE IN INFORMAL URBAN SETTINGS IN BANGLADESH
(BY WAFA ALAM AND IMRAN HOSSAIN MITHU ON BEHALF OF ARISE)

This study looked at exploring health and governance in informal urban settings in Bangladesh. Given the pandemic and the associated mobility restrictions and lockdowns, we were unable to carry out the photovoice method by recruiting community members as we had initially planned. We then planned to simplify the process and instead of recruiting participants for this process, we decided to engage our co-researchers who had already been working with us in participatory GIS mapping exercise (please refer to page 31). Because of the lockdown, it was not possible to recruit community members and organise training or briefing sessions with them, so working with co-researchers was more convenient.

ORIENTATION OF CO-RESEARCHERS ON REMOTE APPLICATION OF PHOTO DIARIES

To begin with, we briefed our co-researchers on the photo diary method on a Google Meet call. We explained that they were required to capture photographs in their community that related to a range of thematic areas, each of which were explained by researchers in detail with examples. Co-researchers asked questions for clarification when needed and shared examples of activities they thought aligned with the themes.

Below are some examples of the themes used in this study:

1. **Community initiatives** (all kinds of activities- awareness building, relief distribution, preventive measures, planning meetings regarding community initiatives).

2. **Situation in the informal settlements** (relief distribution, police activities, shops closed, community protests, making lines, maintaining distances).

3. **Initiatives of Government and other organisations** (private and NGOs) - actions to identify houses in need of support, food and cash support, testing facilities, vaccination programmes, healthcare centres and awareness.

4. **Activities of Community Health Workers.**

5. **Meaning of well-being during lockdown** (vulnerabilities according to co-researchers and the community).

We discussed the ethics of the photo diary method with co-researchers and encouraged that no identifiable photos should be taken of individuals - if required, co-researchers were instructed to take photos from the back/side. We explained that verbal permission should be sought from individuals before their photograph is taken. Asked which type of app they preferred for sharing photos (Facebook messenger, IMO, WhatsApp), and based on their preference, we created a WhatsApp group for each study site and asked them to share photos along with a short narrative, either in writing or in the form of an audio note. We asked that the narrative/audio note include a description of what was happening in the photo, where it was taken, and what the co-researcher thought of the photo.

DATA STORAGE AND INITIAL ANALYSIS BY RESEARCHERS

At the end of every week, the photos, transcribed audio notes and written messages were collated and stored in a shared Google drive. The photos were initially analysed and matched with the narrative by a group of researchers. The researchers then prepared a list of questions that were posed to co-researchers in their weekly reflexivity session.

CO-ANALYSIS IN REFLEXIVITY SESSIONS

- A weekly reflexivity session was arranged with co-researchers (1 for each site).
- In the reflexivity sessions, ARISE researchers and co-researchers discussed the photos from the previous week and asked questions to each other for clarification, co-analysing the content and developing a constructive photo narrative write-up.
- Challenges faced by co-researchers during the process were discussed, as were other issues that required clarification.

WHAT WERE THE BENEFITS OF THE METHOD/APPROACH?

Due to the pandemic and the restriction measures in place, such as lockdown, we were unable to continue field work by physically visiting the study sites. As such, the photos and the narratives sent by co-researchers helps us visualise and understand the actual situation in the study sites.

Photo diaries help bring out the perspective of an individual and to understand how they view their own community, comprising strong evidence that can be used for advocacy. Using the photo diary method also gives co-researchers flexibility in terms of expressing their views and thoughts, as they can send voice notes to the researchers in a group or individually. It also helps to:

- Improve relationships with our co-researchers and the community.
- Strengthen the capacity of co-researchers – initially they were very shy and not comfortable to talk much, but with time they started opening up more and sharing more about their community. In the reflexivity sessions, they participate a lot more.
- Identify the needs of the community from their perspective.

WHAT WERE THE CHALLENGES OF THE METHOD/APPROACH?

One major challenge is the lack of availability of co-researchers for reflexivity sessions. Given that co-researcher engagement is voluntary, co-researchers may prioritise other tasks and it became difficult to find a convenient time for sessions each week. Under normal circumstances, the training for photo diaries would be conducted face-to-face, where we would explain the purpose and give hands on training on how to take photos from different angles. Conducting the training online, however, made it difficult to demonstrate that photos should be taken so that people are not identifiable.

Similarly, conducting briefing sessions and follow up discussions online meant that it was difficult to assess if instructions were clearly communicated and fully understood by co-researchers.

There is a risk that co-researchers may be viewed with suspicion by other community members when they carry out their tasks such as taking photos. Although we briefed co-researchers on the ethics of the method in the training sessions, emphasising the importance of seeking verbal consent before taking photos and explaining the purpose of the exercise, we cannot guarantee that guidelines will be followed by the co-researchers.

One of the ways to address many of the challenges mentioned above is to have regular communication or follow up sessions with the co-researchers. It is important to establish that they can reach out to us at any point (over the phone) to discuss any issues that they are facing in the community. Outside of the weekly reflexivity meetings, we also conduct some follow up/check ins to ensure the work was on track and if not, enquiring why. In one of our community meetings, when the co-researchers were working on GIS mapping activities, we introduced them to the community members in the meeting and explained that the co-researchers were working with us in ARISE. This ensured that people in the community, especially those associated with community development groups and some key gatekeepers, were aware of the role of the co-researchers.

TOP TIPS

- Face-to-face training is preferred when possible (even if the data is to be sent remotely through data sharing platforms).
- On-the-spot immediate troubleshooting and assistance may be required and helps to build trust with co-researchers, and establish a relationship where they know researchers are available to assist them when required.
- Regular follow ups or check-in sessions are useful and help build trust with co-researchers, particularly since the process is remote.
- Weekly reflexivity session with individual teams are helpful, providing a space where teams can discuss different challenges and learnings from the process. It can be useful to document these sessions.
- Monthly reflexivity sessions with co-researchers from all sites can act as a cross-learning platform, enabling co-researchers to exchange ideas and opinions.

BODY MAPPING

INTRODUCTION TO METHOD

Body mapping is a visual technique in qualitative research that explores insights into participants' lived experiences and imagination, which is impacted by their social and cultural context (Klein and Milner, 2019). It is an innovative methodological technique often able to capture the imagination of research participants.

Body mapping can be used as:

- ✅ **A research (data collection) tool**, as a standalone, or in support of other data collection methods when the is need for visualisation of participants experiences and imaginations.
- ✅ **A therapeutic tool** to develop fresh insights, find new directives and explore identity and social relationships.
- ✅ **An advocacy tool:** body maps can be used as exhibitions for advocacy as they are able to raise awareness about political, personal, and social issues.
- ✅ **A dialogue tool to build relationships between groups of people from different backgrounds, ages and disciplines** to appreciate their differences and understand how life affects other people.

Being a time and personnel intensive research method, a high level of engagement with participants is needed (Dew et al., 2018).

HOW TO DO METHOD

In this section, we are going to focus on body tracing, a body mapping technique that traces an outline of the participant's body characterising their experiences and imaginations including who they are, what they do, how they feel and what they expect.

1. Prepare a safe environment for the body mapping activity, taking into consideration participant privacy and confidentiality.
2. Ask participant to draw a sketch of their body or provide pre-drawn body sketches. This can be done by asking the participant to stand, lie or sit in a position that they feel comfortable in and tracing around the participant on paper. Alternatively, you can ask a participant to draw a depiction of themselves to annotate.
3. After tracing the body, ask the participants to annotate the body tracing.
4. Ask participants to identify key experiences and imaginations that affect their bodies, relating to themes of the research.
5. Ask participants to think about symbols or images that capture such experiences.
6. Ask participants to paint or mark the symbols of their experiences and imaginations onto their body tracing.
7. Ask participants to write down the experience or imagination on or beside the symbol/image. This could be written directly on the body tracing or onto sticky notes which can the be stuck onto the body tracing.
8. Ask participants to reflect on the map they have created, discussing how they feel about them and whether there are any additions or adaptations they would like to add. Record the discussion.

Methods adapted from (Klein and Milner, 2019) and (Coetzee, 2019).

RESOURCES NEEDED:

- A4 paper/art paper
- Art materials such as crayons, coloured pens, pens
- Sticky notes
- Adequately sized space/drawing surface
- Camera
- Audio recorder
- Glue
- Scissors
- Paint (washable) and paint brushes

CASE STUDY

USING BODY MAPPING TO UNDERSTAND THE EXPERIENCE AND MANIFESTATION OF DEPRESSION IN ADOLESCENTS LIVING WITH HIV IN ZIMBABWE
(BY WEBSTER MAVHU, LSTM & CESHHAR ZIMBABWE)

A body map is a picture of the body that can show different things (e.g. parts of the body associated with certain activities/feelings).

In 2015, we conducted a body mapping exercise with adolescents living with HIV (ALHIV) in Zimbabwe who had been diagnosed with major depressive disorder (MDD)(Willis et al., 2018). Participants created a painted map of their body to assist them in expressing their emotional and somatic experiences in qualitative interviews. Idioms of distress were conveyed through both their verbal narratives and the words/images which they painted on their body maps.

As with other participatory tools, body mapping provided a non-threatening way to discuss a sensitive topic among ALHIV, a group particularly affected by stigma. The most commonly used terms to describe depression were 'thinking too much' or being 'lost in thought' as result of their life events.

Body maps may invoke unpleasant/traumatic memories. This was especially so for this particular topic and group. To minimise harm, professional counsellors were on standby.

TOP TIP

Body mapping participants are likely to be more comfortable in locations with some privacy and in single-sex groups (if working as groups).

PARTICIPATORY THEATRE/WORKSHOPS

INTRODUCTION TO METHOD

Participatory theatre as a qualitative research method is an innovative way of using performance to engage participants to express their experiences, views, and knowledge. In participatory theatre, participants play out scenes from their everyday life, and together with researchers, they observe, analyse, and theorise about these experiences. This also provides a forum for reflections on power relations and social structures in the participant's context.

Participatory theatre is helpful when dealing with research participants with language barriers and those not confident enough to engage in discussions with researchers.

In this section, we have focused on the Forum theatre as part of the Theatre of the Oppressed, which is a participatory theatre that breaks down boundaries between actors and spectators. In this method, participants play both roles of actors and spectators in a given role. This allows for the expression and observation of structures which lead to oppression and engages participants to reflect on and express how to drive change.

HOW TO DO METHOD

Adapted from (Erel and Kaptani, 2018)

1. Identify a group of participants and explain the process and duration of the workshop.
2. Identify a safe space where participants can talk to each other freely.
3. Train participants in basic theatre skills to learn to use their body as a tool for expression. This can be done through games and exercises.
4. Invite participants to show a scene of their choice on a personal experience of a social problem or issue. Allow other participants to watch the scene.
5. Then invite the other participants to step in the role of the initial actors (protagonist) and suggest an alternative course or expression of the problem or issue that will solve the problem or result in a different outcome.
6. Invite participants to reflect on their roles, the problem/issue and the potential solutions they acted out.
7. Record the entire process , as aligned with protocol (notes, audio, video, etc.)

Forum theatre allows participants to reflect on a collective process of individual interventions, each bringing a new aspect of knowledge to the scene and enabling participants to learn from each other.

> **RESOURCES NEEDED:**
> - Audio/video camera
> - A private, spacious room
> - Flip-charts
> - Stick-on notes
> - Pens

CASE STUDY

EXPLORING CARE PATHWAYS FOR MEN WITH TB IN MALAWI
(BY MACWELLINGS PHIRIAT AT MLW)

We used Participatory Workshops (PWs) to complement in-depth interviews for a study that aimed to understand barriers and develop interventions to improve pathways to diagnosis and care of TB for men in an informal settlement in urban Blantyre, Malawi. After the data from the interviews had been analysed and themes relating to men's treatment barriers identified, we wanted to find solutions to the barriers which were tailored to community needs. The interviews involved men and women and had focused on understanding people's (in particular men's) treatment seeking experiences for TB. The purpose of the PWs was for the communities to further discuss the barriers and to identify and prioritise potential interventions to these barriers.

PWs took an art-based approach and drew on Theatre of the Oppressed as a research method in conjunction with group discussions. To break down power barriers between participants and the research team, we used games and exercises before using Image Theatre. Participants made still images with their bodies to explore gender norms, experiences of sickness and healthcare, which were then discussed as a group. The process continued by developing role plays and finally a Forum Theatre performance for the study team, which demonstrated some of the challenges of men seeking healthcare, and gave opportunities for the audience to suggest and try out different solutions on stage. To allow for open discussion of potentially sensitive gender norms and behaviours, these PWs initially divided groups by gender, working separately with men and women before bringing the two groups together to make the performance. The approach not only helped identify and prioritise potential interventions to the barriers, but also demonstrated how the interventions might work.

Relating to ethics, all the participants provided informed consent, either written or witnessed thumbprint. We also assured the participants that only the study team would access the data generated through the PWs and that the data will be published or presented anonymously. The challenge, though not particularly unique to the approach, was ensuring that participants respected confidentiality and anonymity of other participants as we had no control over their actions after the meetings.

TOP TIP

To keep the participants animated and engaged, we used a variety of energisers. To make the Participatory Workshop engaging, be creative and make the event both explorative and entertaining.

PARTICIPATORY VIDEO

INTRODUCTION TO METHOD

Participatory video is a method or technique designed to engage co-researchers or participants in creating a film or video that tells their story, exploring what is important to them and how they want it to be represented on a subject. The basic principle is to put the equipment (video camera) in the hands of the participants or co-researchers and guide them in taking control of the content of the videos to be created.

Participatory video enables individuals, groups and communities to express themselves on issues that they may not have openly expressed before, while allowing them to explore and experiment with other viewpoints.

Participatory videos can therefore be used as a tool to:

✅ **Explore viewpoints on a topic of interest. This could be part of a reflective process during a project evaluation.**

✅ **Sensitise and or inform communities and stakeholders on a topic of interest or an event.**

✅ **Empower individuals, groups or communities and drive social change.**

✅ **Advocate for needs identified in the community.**

HOW TO DO METHOD

1. Familiarise yourself with all your equipment, taking note what questions participants might ask

2. Sensitise the community about the participatory video you wish to carry out. Discuss the benefits with the community and the possible inconveniencies. You should also discuss how long the process will take and who will be actively involved.

3. Make sure participation is open and voluntary and obtain informed consent from all participants. Train participants on how to obtain clear consent from anyone whose story is being told.

4. Train the participants on how to use the video camera. All participants should receive basic training on:
   - How to turn the camera on and off
   - How to hold the camera and get steady
   - How to press record
   - How to check the sound
   - How to adjust the shot using the zoom functions.

5. Explain the aim of the videos and collectively decide on the audience of the video. This makes participants confident and puts them in control of what they wish and wish not to share in a video. Participants will also be able to take relevant videos that target the project aim.

6. Allow time for participants to practice and share their experience with each other.

7. Collaboratively brainstorm on any questions necessary to ask their audience. Participants can write their questions on sticky notes and display on flipcharts. Collaboratively group questions to show common themes and allow participants to select which stories will be filmed to best meet the aim of the project.

8. Plan the outline of the story. This could be in the form of narrative, one-to-one video interview, a group discussion, a short drama, etc. You should guide participants to keep the aim of the video in mind while they decide on which outline(s) to use.

9. Record the videos. Allow participants to record the videos as planned without interference, except in cases of technical fault of equipment. The more participants are in their comfort zone, the more likely they will engage with their audience for constructive discussions.

10. Edit and compile draft footage.
    - Show each participant their videos at the end of each filming session for them to decide whether to keep or delete.
    - When agreed, show videos to a larger group of participants for them to tell you if they are satisfied or prefer to add or remove certain content.
    - Check that consent was obtained from all persons clearly seen in the videos. Explain to participants the possible risk and problems that may arise due to lack of consent.
    - Make a compilation of the videos using computer software.

11. Share the file with the community and obtain filmed consent.

- Organise a public gathering of participants and key members of the community.
- Play the full video to them.
- Inform them about the broader audience of their video.
- Obtain consent for the video to be shared broadly or detail restrictions if they want.
- Make copies of the videos and share with the community.
- Encourage community members to collect more stories as participatory videos. Cameras can be left with communities for this purpose.

RESOURCES NEEDED:

- A simple video camera: a camera with an on/off, zoom and pause control is sufficient.
- Flipchart papers.
- Sticky notes or coloured cards.
- A computer with software for editing and compiling videos.
- A projector and screen to showcase the final video.

2.3 MAPPING PROCESSES AND STAKEHOLDERS

This section looks at participatory methods which focus on understanding who to engage, identifying key stakeholders as well as exploring challenges to health seeking or care pathways, and reviewing specific programmes or processes. These methods can be used in different ways including to gather baseline data, or to plan for public health programmes. This section will:

✅ **Introduce and provide step by step instructions on conducting participatory methods.**

✅ **Learn about case studies, which have used specific methods.**

✅ **Consider the strengths and challenges of these methods.**

✅ **Learn top tips for each method.**

STAKEHOLDER MAPPING

INTRODUCTION TO METHOD

Stakeholder analysis is the process of identifying individuals or groups (stakeholders) who have an interest in or may be affected by the process and or outcomes of a project or a policy change. They are used to understand the perspectives of these individuals and how likely they are to:

- **Actively contribute to the development and implementation of the project or policy change.**
- **Promote and sustain activities and outcomes relating to the project or policy change.**
- **Be affected by the project or policy change.**

Stakeholder analysis maximises stakeholders' involvement in the development and implementation of the outputs and advocacy for sustainability of the project or policy.

HOW TO DO METHOD

1. Identify the objective of the project or policy change and discuss potential targets and possible impacts of this project or policy change.

2. Identify all stakeholders or groups of interest who are likely to act upon or be affected by the project or policy change. These could be individuals, social groups, institutions or organisations and networks. Create a small group of researchers (ideally 6-8) to brainstorm on these stakeholders and or talk to individuals involved in the project or policy you are trying to influence.

3. Organise stakeholders according to their power and interest in relation to the focal issue.

   - Power refers to the influence stakeholders are likely to have over the project or policy change. It includes to what degree they can help achieve or block the project or policy change.
   - Interest refers to what degree stakeholders are likely to be affected by the project or policy change or what degree of concern they are likely to have in or about it.

Power or Interest levels could be classified as high, moderate, or low, and laid out in the form of a pyramid sometimes known as an **Influence map**.

For example, decision-makers such as government officials are usually found at the top of the influence map, followed by opinion leaders such as community leaders whose voices and opinion matters to the people they serve.


DECISION MAKERS SUCH AS GOVERNMENT OFFICIALS

OPINION LEADERS

OTHERS
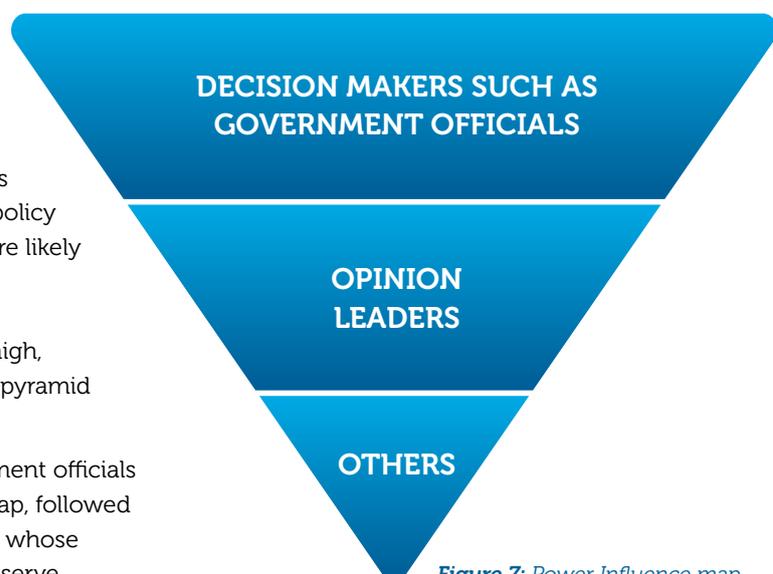
Figure 7: Power Influence map

4. Identify Nature of Power and Interest

Different stakeholders hold different positions and therefore have different power and interest in the research. It is useful to understand this and the impact this may have on the project or policy change. For example, women leaders may wish to take part in a mother and child intervention; youths may wish to participate in the organisation of a youth event.

5. Organise stakeholders into different matrices according to their power and interest using the grid below (figure 8):

- **Stakeholders with high power and high interests** are important to fully engage in the project or policy change (Players).
- **Stakeholders with high power and low interest** need to be kept satisfied and or be engaged as patrons, lobbyists or supporters to the project or policy change.
- **Stakeholders with high interest and low power** should be kept informed on the study. These could form the basis of an interest group which can lobby for change.
- **Stakeholders with low power and low interest** should not be prioritised but monitored in case their power or interest changes.

HIGH POWER, LOW INTEREST Keep satisfied, engage as patrons, lobbyists, or supporters	**HIGH POWER, HIGH INTEREST** Engage in the project/policy change
LOW POWER, LOW INTEREST Monitor	**LOW POWER, HIGH INTEREST** Keep informed

Figure 8: Power-Interest Grid

6. Develop a strategy on how best to engage the different stakeholders. This strategy should include:

- What message to convey to each of them.
- How and when this message should be conveyed.
- Who should convey the message and invite stakeholders to engage in the project/policy change.
- How to maintain a relationship with the stakeholders to keep them on board throughout the project/policy change.

RESOURCES NEEDED:
- Flipchart papers
- Pens
- Power-interest (stakeholder) grid

USING STAKEHOLDER MAPPING/ANALYSIS TO DEVELOP AN NTD COMMUNITY MONITORING TEAM IN LIBERIA

(BY OTIS KPADEH ON BEHALF OF COUNTDOWN)

> *'Stakeholder mapping is a visual process of laying out the stakeholders of the project, product or idea on one map. The main benefit of stakeholder mapping is to get visual presentation of all the people who can influence your project and how they are connected.'*
>
> (Savina, n.d.)

In Liberia, we used stakeholder mapping to engage community members to support the establishment of community monitoring teams that could support NTD programme delivery. During this process, the participants were given the opportunity to share their views and knowledge with the study team. Posters and markers were given to them to document key stakeholders that are essential for the formation of the Community Monitoring Team (CMT) to be used in the conduct of the Mass Drug Administration (MDA).

The community took the lead by appointing one person from the group to write down comments and suggestions about influential groups in the community. The participants listed all the influential groups.

Since there were many groups listed and the CMT needs just four members, the research team again probed for which groups the people forming the CMT should come from.

The following groups were suggested by the participants during the discussion:

1. Teachers
2. Women's group
3. Youth group
4. Religious group

The groups were selected based on their work in the community and the influence they have with people. The participants were happy to participate in the discussion, especially since they were helping to make decisions for their community on health-related issues.

Major challenges experienced during the stakeholder mapping process were:

a. Language barriers
b. Traditional norms, practices and power dynamics (for example; women did not express themselves in gatherings where men were also present.

The team overcame the challenge of language barrier by the use of an interpreter, enabling a smooth and free flow of communication between the research team and the participants.

The research team also asked women for their input directly, providing a space for them to contribute in discussions that were often dominated by men.

At the end of the mapping process, the team established the roles of responsibilities of the CMT, which included raising awareness, monitoring, supervision and timely reporting.

ACTION LOGS

INTRODUCTION TO METHOD

Actions logs can be kept by co-researchers to understand how activities identified in an action plan are implemented or not in a programme or period of time. These reflections can then be mapped against planned or anticipated activities. These observations can be utilised at programme review meetings to encourage wider reflection, or to support the development of interview topic guides to gain more information. They can also be triangulated with other sources of data, such as ethnographic observations, so that a wide range of perspectives and observations are captured.

HOW TO DO METHOD

1. Explain the purpose and intention of the action logs to co-researchers.
2. Gain informed consent from co-researchers.
3. Agree a mechanism where action logs can be fed back to the wider team, such as a phone call once per week, or individual records kept in real time which are collated once per week.
4. Develop Action log template. The example below could be adapted.

DATE	ACTION THAT YOU HAVE TAKEN TOWARDS ACHIEVING PLANNED ACTIVITIES	WHO WAS INVOLVED AND WHAT WAS THE OUTCOME?	WHAT WORKED WELL?	WHAT WILL YOU DO DIFFERENTLY NEXT TIME?	DID THIS DIFFER FROM THE PREVIOUS HEALTH PROGRAMME?	LOCATION

5. Depending on the purpose of these action logs, generate a discussion on the reflections captured and map against anticipated actions.

> **RESOURCES NEEDED:**
> - Action log templates
> - Phone credit or internet access
> - Pens
> - Consent

USING ACTION LOGS TO EVALUATE A NEWLY INTRODUCED PARTICIPATORY APPROACH TO PLANNING AND IMPLEMENTING NTD PROGRAMMES IN NIGERIA
(BY JAMES YASHIYI ON BEHALF OF COUNTDOWN)

We utilised action logs at two points in the COUNTDOWN research process in Kaduna and Ogun, Nigeria. Firstly, they were used to collect data remotely from co-researchers on their activities in relation to MAM during an early phase of community engagement. Later, action logs were used with co-researchers and NTD programme implementers while scaling up a newly introduced participatory approach to planning and implementation of MAM.

THE PROCESS

Co-researchers recruited from the state and local government levels of the NTD programme were paired with COUNTDOWN researchers, to update the latter about activities they carried out during a MAM cycle in line with the action plan developed. The action log template was sent out to each participant to fill with information on the activities they carried out, including during sensitisation, advocacy visits, training of medicine distributors and medicines logistics. Co-researchers sent the filled template via email or WhatsApp back to their paired COUNTDOWN partners either once or twice a week. Once received, we arranged a date and time for a phone interview to discuss in detail the activities highlighted in the template. In Ijebu Ode LGA, one of the study sites in Ogun, a co-researcher sent an action log reporting that she took part in the joint training of recorders, mobilisers and health workers. This was the first time that this combination of people were brought together and trained to distribute medicines - the usual practice to engage only CDDs. The co-researcher reported that these trainees demonstrated a good level of understanding of the training delivered. They arrived at the training venue early and training commenced on time. The co-researcher reported that participants were satisfied with the outcome of the training and had no further recommendations for its improvement. The co-researcher reflected that the decision to conduct joint training with people from three different roles (who will constitute medicine distribution team) was a good innovation that would improve therapeutic coverage in her LGA.

The co-researcher also captured her role in the sensitisation of religious groups and commercial motorcycle riders in the action log, stating that the use of information, education and communication (IEC) materials printed in the local language worked well. She noted that she would print more copies of these materials in future, indicating that more time is needed for the sensitization of diverse groups in the community regarding MAM.

KEEPING TRACK OF THE SCALE UP PROCESS

Tools were developed from evidence collected in the previous phases of the study. Co-researchers and NTD programme implementers were provided with these tools to scale up their use for participatory planning of MAM in different LGAs of the state. They were further trained with soft skills to facilitate training and meetings using the tools provided. While applying the two resources (tools and the training) they filled the templates to enable the research team to evaluate the process and outcome of using them.

Another co-researcher captured in their action log that they participated in a flag off ceremony for MAM. They recorded that the Chief Imam in the LGA and the LGA executive chairman were involved in the activity, which resulted in increased awareness about the programme among residents of the LGA. Regarding 'what worked well', the co-researcher reported that recommendations in the participatory guide for planning equitable MAM helped to emphasise the need to engage widely with different stakeholders to promote the NTD programme. Consequently, the Chief Imam and the executive chairman were visited and invited to take part in the programme, to which they responded positively. On reflection, the co-researcher said that they intended to extend the engagement to other groups such as migrant groups and other under-served groups in the community for subsequent MAM planning and implementation.

THE INTERVIEWS

The interviews conducted added details to the information provided on the template. For instance, the local level implementer explained that the flag off ceremony for MAM by the Chief Imam and executive chairman did not happen by default, rather it was outcome of visits taken to these religious and political leaders that led to their participation in the ceremony. The Co-researcher added that the Chief Imam and executive chairman made financial contribution to the programme. These details were provided by the co-researcher during phone interviews and were not recorded on the logs. We recorded these interviews and further updated the logs.

VALUING THE APPROACH

Both the details on the template received via email and WhatsApp and the recordings from the phone interviews were converted into narrative reports and synthesised with other evidence to finalise resources that will contribute to the improvement of the NTD programme in the country.

The approach proved to be useful in the two scenarios we utilised it. Firstly, it provided us with feedback on the action planning template we co-created in the research. Secondly, we got feedback on the process and outcome of using the tools and skills cascaded during the scale up process. Both sets of feedback contributed to the body of COUNTDOWN evidence supporting the uptake of tools provided as part of the NTD programme.

TOP TIP

Action log templates can be used as a topic guide for researcher/co-researcher dialogue. If there are internet difficulties or issues with literacy, hard copies of action logs can be completed during the conversation, rather than prior.

PARTICIPATORY PATHWAY: HEALTHCARE SEEKING PATHWAY ANALYSIS CASE STUDIES

INTRODUCTION TO METHOD

Health seeking pathways describe the steps that people take from the onset of symptoms to when they can get the care that they need for a particular disease or condition. It is expected that everyone with a medical need should seek care from appropriate caregivers or care-giving facilities. However, due to social, economic, cultural, and structural barriers, people use different health seeking pathways to get the care they need. Healthcare seeking pathway analysis therefore seeks to understand the challenges and barriers that limit people or communities from accessing the ideal care they need.

Care seeking pathway analysis can be carried out by a research team in collaboration with stakeholders and members from the community of interest.

HOW TO DO METHOD

1. Identify the disease or condition to which you will apply healthcare seeking pathway analysis.
2. Identify the community or persons that you will focus on.
3. Describe the ideal pathway for the disease or condition. This is done via a step-by-step process of identifying what people should do at every stage from the onset of symptoms to getting the care needed. This can be described by answering the following questions in relation to the disease or condition:
   - At the onset of the disease or condition, where should patients go to seek help? Who should make that initial decision? How should the patient get there?
   - On arrival at the health facility, who should see the patient? How should a diagnosis be made? What treatment should be given to the patient? How and when should this treatment be given? How should the patient be counselled about the disease or condition?
   - After receiving treatment, how should the patient be followed up? Who should follow-up the patient?
4. Describe the actual pathway people take to seek care for the disease or condition. In this section, you should identify what actually happens from the onset of symptoms to when the patient gets the care needed. This can be described by answering the following questions:
   - At the onset of disease or conditions. Where do patients go to seek help? Who makes the initial decision to seek help? How do patients get there?
   - On arrival at the health facility, who receives the patient? How is the diagnosis made? What treatment is given? How and when is this treatment given? How is the patient counselled about the disease or condition?
   - After receiving treatment, how is the patient followed up? Who follows up the patient?
5. Compare the ideal pathway with the actual pathway and explore the barriers and challenges prevent people from utilising the ideal pathway. In this step, you should:
   - Place the ideal pathway alongside the actual pathway of the patients.
   - Identify the differences between the two pathways.
   - Discuss the reasons why people could not access the ideal pathway.

RESOURCES NEEDED:

- Flipchart papers
- Pens
- Stick-on notes

CASE STUDY

UNDERSTANDING FEMALE GENITAL SCHISTOSOMIASIS HEALTH-SEEKING PATHWAYS IN LIBERIA
(BY MOTTO NGANDA ON BEHALF OF COUNTDOWN)

COUNTDOWN
Calling time on Neglected Tropical Diseases

The COUNTDOWN FGS study in Liberia is a primary health care intervention study that aimed to develop and pilot a health package for diagnosis, treatment and management of women and girls with symptoms of FGS in areas highly endemic for schistosomiasis in Liberia.

This participatory activity was carried out by health workers and close-to-community care providers in our study context, in collaboration with the research team. We used case scenarios of women and girls at different stages of life and disease progression to determine 1) an ideal pathway these women and girls should use to seek care, and get a diagnosis and treatment; and 2) the actual pathway these women and girls use to seek care, get their diagnosis and treatment. We drew comparisons between these two pathways to determine the gaps in the pathways, and to understand the challenges faced by these women and girls.

CASE SCENARIOS:

CASE SCENARIO ONE

Gartee is 9 years old and lives at home with her mum. She often goes to the lake to play on her way home from school and also to do household tasks like washing clothes and fetching water. She has been complaining for a few months about pain in her tummy and when she goes pee-pee she sees red water.

CASE SCENARIO TWO

Kebeh is a 29-year-old women who has been living with her family in Tuota village for 8 years. With no pipe-borne water at home, she and her family fetch water from the St. John river for household bathing and cooking. She has a 7-year-old son and has since then been trying to have another child but has had one miscarriage. Her husband is tired of her complaints of pains each time they have sex despite the many times he has taken her to the clinic.

For each case scenario, participants discussed the following questions for the ideal and actual pathways:

IDEAL PATHWAY	ACTUAL PATHWAY
What are the symptoms of FGS? How are they referred to in Liberia?	What are the possible symptoms of FGS in Gartee/Kebeh? How will these be recognised locally?
Who should be involved in a patient's decision to seek care?	What would this patient do? Where would she seek care? Who will be involved in their decision to seek help?
What should happen when the patient arrives at the health facility?	What will happen when (if) she arrives at the health facility?
How should FGS be diagnosed?	How is FGS currently diagnosed? How is Schistosomiasis currently diagnosed?
How should patients who receive a positive diagnosis be treated? How should diagnosis be communicated?	How are patients currently diagnosed with FGS/ Schistosomiasis treated? How are they told about their diagnosis?
Where should patients who receive a positive diagnosis be referred?	Where are patients who receive a positive diagnosis referred to?
How should FGS be treated?	How is FGS currently treated?
What happens if FGS is not treated and if FGS is treated late?	What will happen if FGS is not treated or treated late?
How should FGS patients be followed up?	How are FGS patients followed up?

To explore the barriers and challenges to care seeking, diagnosis and treatment, participants put the developed ideal pathway alongside the actual pathway and identified existing barriers women and girls face in getting the required diagnosis and treatment. An example of barriers and challenges identified are given in the images below:
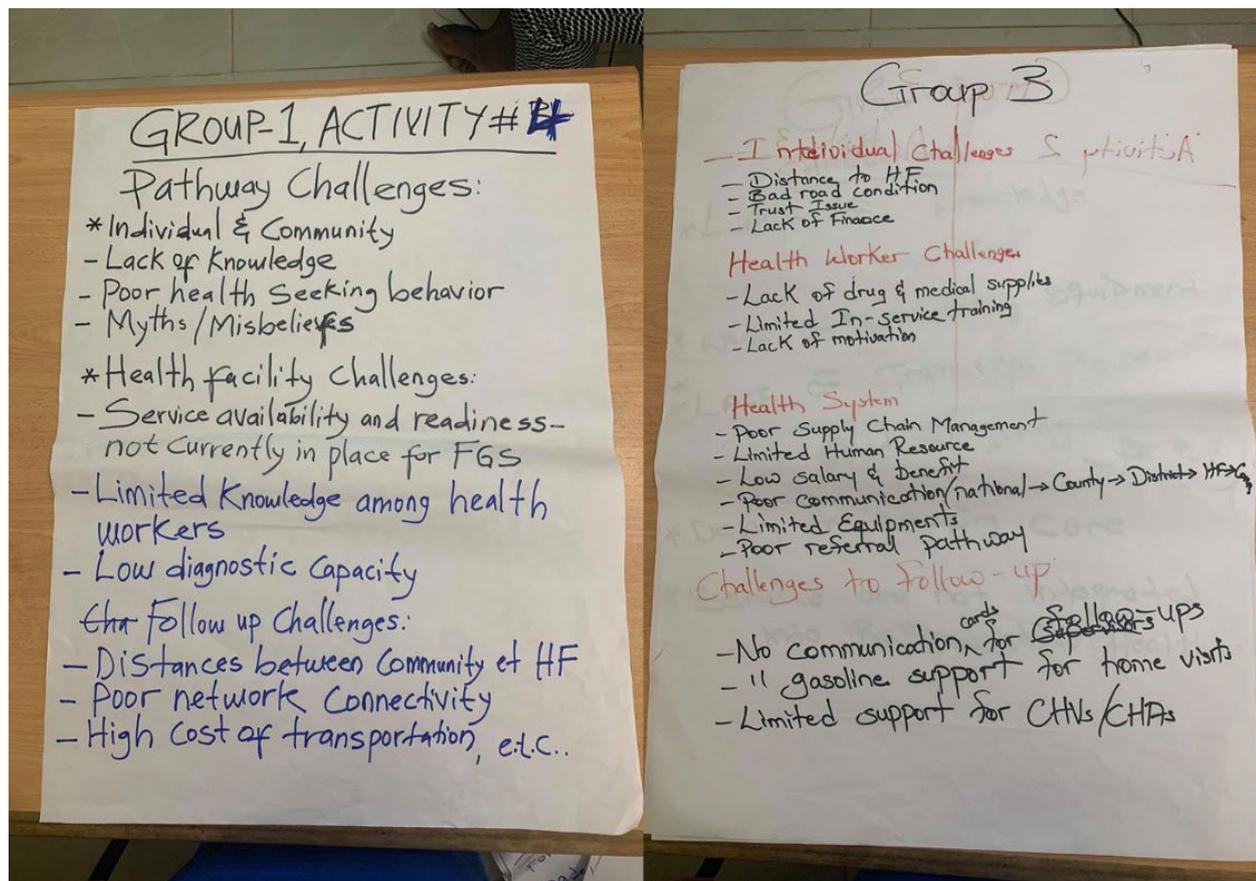
This method led to the identification of context-specific barriers and challenges women and girls face trying to seek care, get diagnosed and receive treatment when presenting with symptoms of FGS. It spearheaded the production of resource materials for primary health workers and close-to-community care givers such as job aids and referral pathways targeting the barriers and challenges identified.
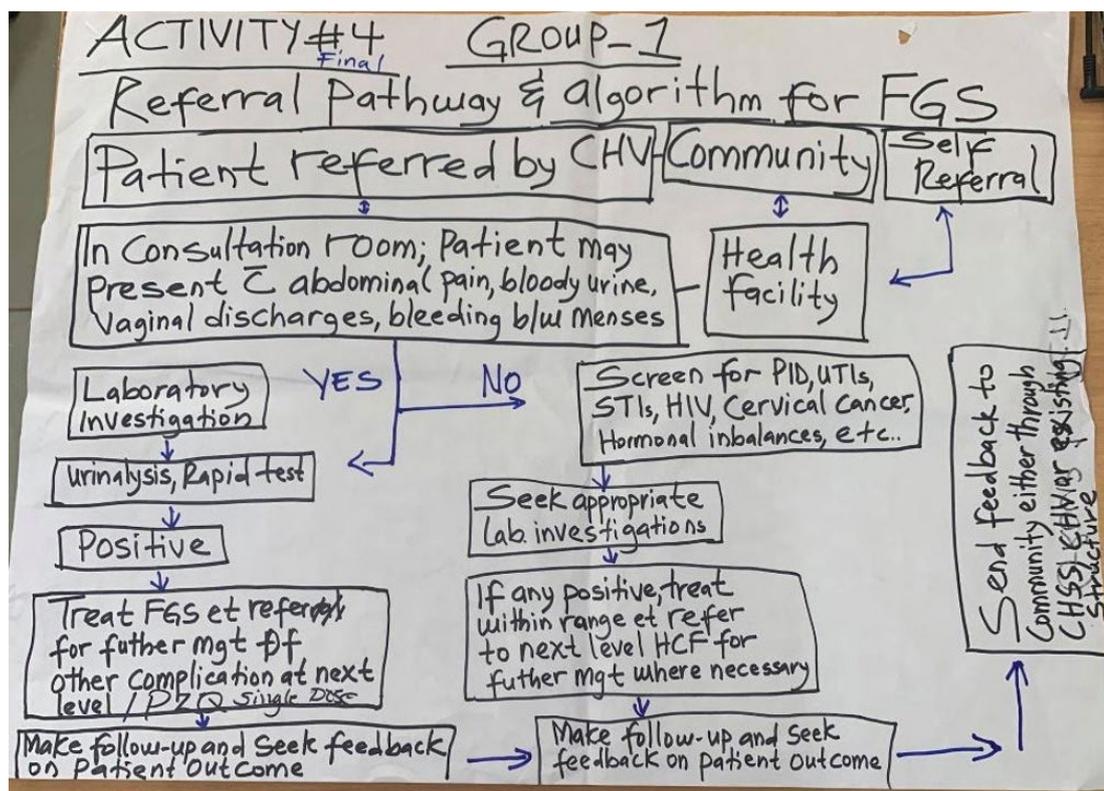
PARTICIPATORY PATHWAY: STEPPING STONES

INTRODUCTION TO METHOD

The Stepping Stone method can be used with community members and co-researchers to jointly determine what steps are needed to achieve an outcome. It is similar to the healthcare seeking pathway as described on page 67. It is important to include a wide variety of participants so that different perspectives can be gathered on a topic, for example a particular health programme or a need identified by the community. It is a co-learning process

and encourages participants to think about their own lived experience and knowledge, so that solutions can be developed which are appropriate for the context and lived reality of communities. Stepping Stones uses a fictional example of crossing a river. On one side is the current challenge or issue, and on the other is the imagined outcome or aim of the programme. The group can collectively decide what steps are needed to cross the river. This method can be carried out with an external facilitator or with no facilitator so that the group self-directs without further prompting.

HOW TO DO METHOD

1. Explain the purpose of the activity and gain consent from participants.
2. Mark an area in an open space to portray a river which needs to be crossed. You can do this with rope or markings on the floor or table.
3. On one side of the 'river', write the current issue or problem on a piece of card. On the other side of the 'river' write out the intended outcome.
4. Give the participants pieces of card and pens and ask them to write out what steps are need to reach the other side of the 'river'.
5. The participants should discuss the potential steps and solutions. You can choose to use a facilitator to guide this process, or the participants can self-direct the process.
6. Once the participants have a number of steps, ask them to arrange them in order of importance/priority.
7. Following this process, you can ask the participants what challenges they anticipate with each step and what resources would be required.
8. Audio record the discussion if the participants agree. Alternatively take photographs of the steps so they can be documented.

RESOURCES NEEDED:

- Consent forms
- Rope/chalk
- Pens
- Flipchart paper
- Card
- Audio-recorder
- Camera
- An appropriate environment which is safe, has enough space and has limited distractions.

USING STEPPING STONE AS A PARTICIPATORY HEALTH RESEARCH METHOD IN NIGERIA TO DESIGN CARE INTERVENTION FOR WOMEN AND GIRLS WITH FEMALE GENITAL SCHISTOSOMIASIS
(BY AKINOLA OLUWOLE ON BEHALF OF COUNTDOWN)

COUNTDOWN
Calling time on Neglected Tropical Diseases

As part of the COUNTDOWN Study in Nigeria, we used the stepping stone method to engage health system actors to design a care pathway for persons affected by FGS. We decided to use this approach because we wanted a holistic and sustainable solution that involved systematic steps/pathways embedded within local settings in Nigeria.

Stepping Stones enabled participants to think through the problem and provide context specific solutions:

- ✅ **It is a co-learning process that encourages participants to think about their own knowledge and lived experiences in relation to the issue at hand.**
- ✅ **It encourages collective brainstorming of ideas to offer practical solutions to health problems or challenges.**
- ✅ **It can be used to initiate the development of a novel framework for addressing a problem or challenge.**
- ✅ **It is useful for better understanding of the resources needed for providing sustainable solutions.**
- ✅ **It helps to identify the various stakeholders that need to be engaged to get a desired outcome. All stakeholders contribute different knowledge and can identify different challenges and solutions based on their collective experience.**
- ✅ **It encourages the use of available resources**
- ✅ **It can be used with people of different cadres and backgrounds.**

Stepping Stones requires a large free space for a successful implementation. It is time consuming as you need a minimum of an hour; therefore, participants could get tired along the way. It is also important to consider individual(s) or group(s) that may dominate the discussion if not well facilitated.

To address these challenges, we organised a venue with a large free space for the meeting. We encouraged participants to concentrate and indicated beforehand how long the session would take. We collectively set ground rules at the start of the meeting to encourage participants from all participants.

TOP TIP

The Stepping Stone method is useful when thinking about solutions that require multiple, systematic steps to achieve the desired outcome. Strong facilitation skills are important to effectively implement the method.

CASE STUDY

USING STEPPING STONES TO UNDERSTAND THE STEPS ON THE JOURNEY TO BECOMING A PATIENT ADVOCATE IN LIBERIA
(BY ROSALIND McCOLLUM ON BEHALF OF REDRESS)

Within Liberia, people affected by SSSDs are often stigmatised and experience discrimination and isolation as a consequence of their condition. There are no known patient advocate groups among people affected by SSSDs within Liberia. However, there are patient advocate groups for other chronic and/ or stigmatising conditions.

WHY USE STEPPING STONES?

We used the Stepping Stones method to understand what the steps were to becoming a patient advocate in Liberia. We recruited 48 participants who were patient advocates for people with conditions associated with stigma in Monrovia, for example those with disabilities, mental illness, or who contracted Ebola Virus Disease. We hoped that REDRESS could learn from these advocates and identify common steps which could help facilitate the creation of a patient advocate group among people with SSSDs.

Participants were grouped according to gender and health condition, enabling us to look in depth at the factors which enabled them to become a patient advocate. Each group was encouraged to imagine that they were standing on one side of the river with their health condition (e.g. mental illness). On the other side of the river was a person affected by the same condition (e.g. mental illness) who was a patient advocate. The group then identified the steps , which represented attributes or conditions, necessary to enable them to cross from one side of the river to the other in order to become a patient advocate (see photos 1 and 2).


Photo 1: Stepping Stones identified to becoming a patient advocate

Photo 2: Stepping Stones identified on the journey to becoming a patient advocate (EVD survivors group)

We found Stepping Stones to be a valuable way to encourage participants to identify and reflect together on the steps that led to them becoming patient advocates. Participants were encouraged to think about timelines, and the order in which the steps occurred and linked to each other in their journey to becoming an advocate.

The activity sparked further discussion around the steps identified. For example, facilitators probed to find out why a certain step was important, what skills were required for that step, and how able participants felt to take the step.

Through involving a group of participants in a group setting, rather than a single participant in a life history discussion, the group discussion enabled the identification of common steps among participants.

The value of using Stepping Stones with patient advocates is that they have already made the journey to become an advocate. However, there may have been difficult or traumatic steps along a person's journey to becoming an advocate, which may bring some distress for participants to recall. Where this occurred the participant was given the option to take a break from discussion, until he/ she felt ready to participate.

Photo 3: Stepping Stones with women who are EVD survivors

Photo 4: Stepping Stones method with women with disabilities

TOP TIPS

- Consider innovative ways to set up the room to encourage participants to think about crossing from one side of the river to another, e.g. positioning chairs to look like the river banks (see photos 3 and 4).

- Create a 'safe-space' group environment for participants where they will feel able to share their stories. Allow time for participants to take breaks from the discussion if needed.

- Consider using life histories as a way to follow-up after the Stepping Stones group discussion, to collect more in-depth understanding from selected participants.

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